

**THE CARING ‘OTHER’: DIMENSIONS OF HOME-BASED NURSING IN
KERALA, INDIA**

**A thesis submitted during 2022 to the University of Hyderabad
in partial fulfilment of the award of a
Ph.D. degree in Anthropology**

**by
Anakha Ajith
(16SAPH02)**



Department of Anthropology

School of Social Sciences

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(P.O.) Central University, Gachibowli,
Hyderabad – 500 046
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CERTIFICATE

This is to certify that the thesis entitled **“The Caring ‘Other’: Dimensions of Home-based Nursing in Kerala, India”** submitted by **Anakha Ajith**, bearing Registration Number **16SAPH02** in partial fulfilment of the requirements for the award of Doctor of Philosophy in **ANTHROPOLOGY**, is a bonafide work carried out by her under my supervision and guidance.

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1. Ajith, A. (2020). In the Pursuit of an Identity: Analysing the Case of Male Health Care Providers. *Masculinities and Social Change*, 9(3), 310-336.

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And has made presentations in the following conferences:

1. A paper entitled **‘Another Set of Angels: Stories from an Anthropological Study of Home-Based Nursing in Kerala’** at ‘Graduate Research Meet 2018’ held at Indian Institute of Technology, Guwahati, during 26-27 October 2018. (National)

2. A poster entitled **‘A Helping Hand for the Disabled Elderly: The Study of Home-Based Nursing Care in Kerala, India’** in the international conference on ‘Evidence in Global Disability and Health’

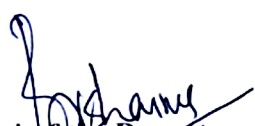
2. A poster entitled 'A Helping Hand for the Disabled Elderly: The Study of Home-Based Nursing Care in Kerala, India' in the international conference on 'Evidence in Global Disability and Health' jointly organised by SACDIR- Public Health Foundation of India and ICED- London School of Hygiene and Tropical Medicine, during 26-27 February 2018. (International)

Further, the student has passed the following courses towards the fulfilment of coursework requirement for Ph. D:

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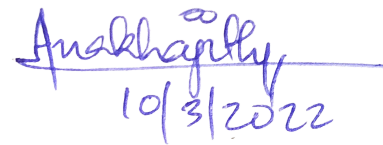
DECLARATION

I, Anakha Ajith, hereby declare that this thesis entitled “**The Caring ‘Other’: Dimensions of Home-based Nursing in Kerala, India**”, submitted by me under the guidance and supervision of Professor BV Sharma, is a bonafide research work. I also declare that it has not been submitted previously in part or in full to this University or any other University or Institution for the award of any degree or diploma.

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Chapter 1

Introduction

This introductory chapter attempts to clarify certain concepts that are relevant to research on nursing in general, and home-based nursing in particular. The most substantial research concern of social science scholars in the areas of nursing and domiciliary care are presented. Subsequently, the nature of the involvement of anthropologists in nursing studies, as well as the merits of such involvement, is delineated. Finally, the changes in the care services and the need for research on the care providers and receivers in these changing contexts is outlined to serve as background information for the present research.

1.1 The Role of Nursing in Healthcare

Nurses have, over the centuries, played a crucial role in the healthcare systems across countries. Though the phrases have attracted criticism from various corners, nurses are often dubbed “angels of mercy” and “unsung heroes”. Recognised as the “largest occupational group in health globally”, nurses “provide an enormous amount of care and treatment worldwide” (WHO, 2017). Research has acknowledged their considerable “contribution to successful patient outcomes in a variety of care settings - from acute and tertiary care to prevention and wellness programs” (Chhugani & James, 2017, p.23). Their role in “delivering primary and community care has been recognised as key to achieving universal health coverage” (WHO, 2020). Discussions concerning health professionals’ roles have focused on “two normative models placed in opposition - ‘care vs. cure’. To many, the cure model has been associated with physicians, and the care model with nursing and the other allied health professions” (Baumann et al., 1998, p.1040).

1.2 Nursing and The Concept of Care

The existing literature presents a variety of definitions for the concepts ‘care’, ‘caring’, and ‘caregiving’. While some scholars prefer using one term to another, others use these terms interchangeably. Ousey & Johnson (2007) hold the view that the general population perceives nursing and caring to be the same, and to them, a nurse is someone who will look after their physical and emotional needs if they are hospitalised (p.152). The attribute of care has been pivotal to nursing, an academic discipline and a profession (Parse, 1999, p.275). The present study’s focus is the “vocation” of nursing, which has caring as its core and essence (Watson, 2009, p.144). It has been claimed by Ousey & Johnson, among others, that caring transcends the aspect of physical presence and includes making sense of “verbal and non-verbal communication signs from the patient” (2007, p.152).

The concept of care has sparked much debate and discussion among the academia that there are various definitions of it. Ousey & Johnson talk about the elusiveness of the concept owing to the discord regarding its definition (2007, p.152). However, a few of the popular definitions of the concept are introduced here.

As per the Oxford dictionary, caring is “the work or practice of looking after those unable to care for themselves, especially on account of age or illness” (Oxford Dictionary, 2013).

Baines, Evans, and Neysmith (1998) defined care as “the physical, mental and emotional activities, and effort involved in looking after, responding to, and supporting others” (p.3).

Duffy (2011) has compiled some of the definitions of care. She cites Cancian and Oliner, for whom care is “feelings of affection and responsibility combined with actions that provide responsively for an individual’s personal needs or well-being, in a face-to-face relationship” (p.9).

The author also notes the definition put forth by Tronto and Fisher, according to whom “care is a species activity carried out to live better lives” (p.14).

Several researchers, including Hale, Barrett, and Gauld (2010), adhere to the definition of care propounded by Arlie Hochschild. They believe that care is an emotional bond in which the caregiver feels responsible for the cared-for person’s well-being and does mental, emotional and physical work to accomplish that responsibility (p.94). It is supposed that ideal caring relationships are characterised by “the carers’ concern, worry, consideration, affection, and devotion toward the cared for” (Waerness & Ringen, 1986, p.164). Duffy (2011) also backs the idea of care being engrained in relationships between the parties involved. As per Turpin et al. (2012), “a positive client-nurse relationship entails having comfort and being connected within the relationship” (p.457).

Phillips, Ajrouch, & Hillcoat-Nallétamby (2010), who expounded the notion of care, cited Tronto (1993) to underline the qualities of “attentiveness, responsibility, competence and responsiveness as the four ethical elements of good care” (p.43). As stated by them, care involves giving and taking assistance in a supportive way. The authors elaborate:

Care is embedded within a relationship, value-laden, active as well as passive, powerful as well as disempowering. Care can be seen as a holistic notion pervading all human relationships and activity. Care is a central part of life, binding together families, friends and communities. It is embedded in social relations. Care therefore also embodies love, solidarity, exchange, altruism and spirituality (Phillips et al., 2010, p.42).

Referring to Hilary Graham's (1983) idea of caring as 'labour of love', Kröger (2009) notes that researchers worldwide have highlighted that care is constituted by two vital elements, work and emotion. It is indicated that "the physically and mentally demanding work of caring does not have value if it is performed without any reference to an emotional bond and a normative context" (Kröger, 2009, p.400). Buch (2015) cited the works of several others to detail the dual connotations of the concept. Care is both "an affective concern (caring about) and practical action (caring for)" (p.279). In a similar vein, Waerness & Ringen (1986) observe that "caring about is primarily feelings, and caring for, primarily work" (p.164).

While the larger part of care researchers conceded the difficulty in introducing a universal definition, some attempted to unify the concept. After analysing the literature on the concept, Thomas (1993) determines that "there are seven dimensions common to all concepts of care" (p.651). These dimensions are:

The social identity of the carer, the social identity of the care recipient, the inter-personal relationships between the carer and the care recipient, the nature of care, the social domain within which the caring relationship is located, the economic character of the care relationship and the institutional setting in which care is delivered (Thomas, 1993, pp.651-653).

The author claims that "a 'unified' concept of care can be constructed by combining all of the constituent elements of the existing range of concepts" (p.665). Thus, according to her:

Care is both the paid and unpaid provision of support involving work activities and feeling states. It is provided mainly, but not exclusively, by women in either the public or domestic spheres, and in a variety of institutional settings (Thomas, 1993, p.665).

While many authors deliberated on the care relationships, a few touched upon the power differential that exists in the relationship. Kröger (2009) calls attention to the cared-for person's subordination attributable to the dependency on the caregiver (p.401). It is also identified that care "symbolises confinement of disabled people into institutions and their lives controlled by others, such as professional social workers, care providers, and other family members" (p.403). However, research by Waerness & Ringen (1986) supports the notion that it is one's right to be cared for by people with whom ties of family, friendship or love are shared (p.165).

1.3 Conceptual Definitions

The concept of care, as already mentioned, has quite a few definitions. The present study on paid caregiving uses the one put forth by Cancian (2000), whose working definition of caring is:

A combination of feelings of affection and responsibility, with actions that provide for an individual's personal needs or wellbeing in a face-to-face interaction (Finch and Groves, 1983). Care work includes both feelings and effortful, goal-directed activity, and it centers on responding to an individual's needs. I use the term the value of caring to include both the prestige and respect given to paid and unpaid caring work, and the wages of paid care workers compared to the wages of workers in other occupations. I evaluate care as good insofar as it meets the care receiver's needs for care. Systems of caring are likely to be a mixture of good and bad, since the needs of care receivers have many dimensions and will be defined differently by caregivers, care receivers, outside experts, and other parties. Evaluating systems of caring, therefore, will be complex and open to question, although

making such evaluations is essential to organising caring in an intelligent and morally defensible way (Cancian, 2000, p.137).

As the present study revolves around care work and paid caregivers, an explanation of the definition adhered to is required. Dill, Price-Glynn & Rakovski (2016) use the term ‘care work’ to refer to “occupations in which workers provide face-to-face services that contribute to the physical, mental, social, or emotional well-being of others” (p.335). By using this definition, it is believed that care work contributes not only to physical wellness but also to the overall well-being of the cared-for persons.

Stone (2000) explains why the term ‘caregiver’ is preferred to ‘care worker’. She notes that the latter has a contractual element and contrasts it with the former, based on personal relationships. She reveals that none of her study participants referred to themselves as ‘workers’. Thus, it is stated that “applying the term ‘worker’ to them misrepresents how they think of themselves” (p.93). Nonetheless, the present study uses the terms ‘caregiver’, ‘care worker’, and ‘care provider’ based on the context. When a personal and affectionate connection exists between the carers and the patients, the label ‘care worker’ is avoided. Unlike the participants in Stone’s (2000) research, a handful of the home care nurses in this study have formal relationships with the patients and consider the caregiving process as contractual. The term ‘care worker’ has been used in such instances. The terms ‘caregiver’, ‘formal caregiver’, ‘care provider’, ‘live-in care provider’, and ‘in-home care provider’ are used to refer to the category in general. The term ‘home nurse’, the in-home caregivers’ title in the study area, has been used besides the above expressions.

Since the caregiver is often perceived as a female, the next section will delve into the link between care and gender.

1.4 Care and The Gender Issue

Needless to say, caring for their family members has been considered the role of women and mothers since time immemorial. Care, nurturance, affection, and warmth are often considered the attributes of women. Caring is deemed to be “an expression of the ‘feminine’ and a part of the socially constructed self-identity of women” (Thomas, 1993, p.655). Several scholars scrutinise the gendered division of roles across societies and the familial caregiving duties assigned to sons and daughters differently.

While discussing the case of the American society, Duffy (2011) points out the feminist understanding that “the gendered division of labor is one of the linchpins of systematic gender inequality” (p.2). Gerstel & Gallagher (1994) also highlighted the American belief that adult women are more responsible than men “to provide personal and household assistance” to the family members in need (p.519). Similarly, numerous researchers across the globe seem displeased with the attribution of care to a particular gender. Here are a few accounts that testify this dissatisfaction:

Phillips, Ajrouch, & Hillcoat-Nallétamby (2010) admit that care is a gender issue that needs to be moved into the public sphere, and women remaining predominantly in this low-status activity should be avoided (p.45). It has been emphasised by Waerness & Ringen (1986) that “the issue of caring is of importance not only in social policy but also in relation to changes in the roles assigned to women and their status in society” (p.164). Gregor (2007) argues that “feminists who studied women’s work reveal that their job is often counted as unskilled, as a manifestation of women’s natural tendencies and therefore not as work” (p.32). Ward-Griffin and Marshall (2003) acknowledge the socialist-feminist perspective for considering “female caregiving as highly

skilled emotional, mental, and physical work that crosses ‘public’ and ‘private’ boundaries” (p.204).

1.5 Gender and the Profession of Nursing

Studies have emphasised that no economic value or status is attached to nursing as “gender ideology expects nurses to ‘care’ without questioning what it actually entails” (Bolton, 2005, p.175). Akin to many other studies, several participants in Bolton’s study also believed that women made better nurses. Globally, barring a few countries with a substantial number of ‘male’ nurses, nursing has been a female-dominated field. Statistics from studies conducted worldwide offer evidence that most of the caring occupations are female-concentrated. For instance, “in the U.K., four out of five paid carers are women and, in the USA, 89% of direct care workers (e.g. personal care assistants, health care aides, home care aides) are women” (Bowlby, McKie, Gregory & Macpherson, 2010, p.130). Studies undertaken in India and other Asian countries also reveal that women outnumber men in the care work sector (George & Bhatti, 2019; Jayapal & Arulappan, 2020).

Gender, identified as a hindrance to performing care work, has been delimiting men’s freedom as they involve in occupations that are primarily bodywork. Twigg, Wolkowitz, Cohen & Nettleton (2011) explain the construction of males as “potentially sexually predatory”, limiting their access to bodies. On the other hand, women “are accorded greater freedom, their intervention being interpreted as sexually neutral or safe” (p.178). This is believed to result in “a preference for receiving care from women” (p.178), whose touch is assuaging than that of their male equivalents.

Duffy (2011) states that “many nurturant care occupations are strongly feminised whether that labor takes place in a private home or a public institution” (p.119). The author adds that the

care work performed by nurses, teachers and child-care workers are not valued enough by society partly due to “its association with the purported feminine character of relationship” (Duffy, 2011, p.127). When the case of professional nursing is considered, gender segregation between medicine and nursing is observed. Porter (1992) discourses how gender affects nursing and notes that the segregation mentioned above “is largely founded on the social construction of a skills/caring dichotomy” (p.510). Several others attribute this occupational segregation and the disproportionate representation of women in caring jobs to their lower pay (Rummery & Fine, 2012; Bowlby, McKie, Gregory & Macpherson, 2010).

A number of economists have looked at the lower monetary value associated with women’s jobs. Ghosh (2018) notes:

India has one of the largest gender gaps in wages to be found anywhere in the world, with women’s wages on average only around two-thirds that of men’s wages. Related to this, the occupations in which women dominate tend to be lower paid - and the wage penalty extends even to men doing similar work, such as in the low paid care sector. This is certainly true of private employers (Ghosh, 2018, p.33).

1.6 Men in ‘Women’s Job’

The works of Bullough (1994), MacPhail (1996), Meadus (2000), among others, underscore that “nursing is not a field alien to men though women have established a monopoly over it since the last few centuries” (Ajith, 2020, p.313). However, the recent decades have witnessed an “upsurge in nursing becoming a career alternative for men mostly owing to migration that resulted in the job’s improved status and prospects” (Ajith, 2020, p.314). Despite this trend,

men continue to be portrayed as aliens in the profession, and their masculinities are subject to suspicion “since ‘real’ men are not naturally capable of performing caring activities” (Mackintosh, 1997, p.235). While Macintosh (1997) and Anthony (2004) cite these hindrances men face in the professions, others such as Williams (1995) and England & Herbert (1993) discuss the benefits like better earnings and easier promotions male nurses have due to their superior minority status.

1.7 Nursing in India

In India, nursing continues to be a profession numerically dominated by women. The literature survey on nursing in the country yields results that majorly focus on the migration of nurses (Percot & Rajan, 2007; Roberts, 2012). The nursing shortage in India, with particular reference to the international migration of nurses, has been of interest to some authors (Gill, 2011). According to Nair &Healey (2006), the work of nurses is “troubled by status anxieties as the idea of nursing as dirty work seems to have become culturally embedded in the Indian context” (p.15). Despite the intrinsic rewards it offers, nursing has been a taxing job as it “entails a huge level of dedication and commitment” (Chhugani & James, 2017, p.24). Some scholars have deliberated the challenges faced by clinic-based nurses. The core concerns include long work hours, low payments, exacting night shifts, workplace mental violence, poor nurse-patient ratios due to shortage of staff, assignment of non-nursing roles, and lack of recognition (Chhugani & James, 2017; Nair & Healey, 2006).

1.8 Nursing and Anthropology

Numerous scholars have made efforts to highlight the association between the disciplines of Anthropology and Nursing. Dougherty and Tripp-Reimer (1985) discuss the contribution of nursing to medical anthropology and the influence anthropology has had on nursing. The authors

claim that though “the term ‘health care’ subsumes nursing and medicine, unfortunately, anthropologists have frequently equated health care only with medicine” (p.219). The paucity of anthropological studies on nurses stands testimony to this view. It is argued that many researchers have been erroneous in categorising nursing as a part of medicine. They state, “medicine is primarily concerned with disease, its etiology, pathophysiology and treatment whereas nursing is defined as the diagnosis and treatment of human responses to actual or potential health problems” (Dougherty and Tripp-Reimer, 1985, p.220).

After drawing a clear contrast between medicine and nursing, the duo state that the “focus on client’s culture has a long history in nursing, particularly in public health nursing” (p.220). The significance of the inclusion of social sciences, especially anthropology, in the study of nursing has been highlighted. In this instance, the authors comment on the existing research on the culture of nursing. They find that the themes covered by the writers so far are “the societal view of the nurse, the history of women in nursing, the role of the nurse, changes in the nursing profession, and socialisation of student nurses” (p.221). An analysis of the research on nurses in India also reveals that nursing’s status in society and the profession’s linkage with gender are the significant themes covered.

While contemplating the contribution of Nursing to Anthropology, they emphasise the concept of care. Since the provision of care has been at the centre of nursing, and caregiving involves collaboration and relationship building between the various stakeholders involved in the process, the area has become one of interest to anthropologists. Scholars claim that we cannot do away with human interaction and face-to-face relationships in the caregiving process, even in an age ruled by technological advancements (Ghosh, 2019). Various nursing researchers have

underlined the worth of cultural context in the caregiving process, thereby testifying the need for an anthropological perspective in nursing.

“Culture shapes both the experience of illness and that of giving care, and informs the ways that these roles are perceived by others” (Barg, Keddem, Cohen & Henderson, 2013, p.177). The authors claim that care can be perceived as any of the following:

- A product of loving relationships,
- A commodity in an industry of service providers, or
- A part of social services or a governmental policy (p.180).

They differentiate between what most researchers conclude caregiving is and how caregivers define the same. It is stated that caregiving is more than attending to medical care tasks. Being with the patient and giving them company, which might appear trivial, is also a part of the caregiving process. This leads them to conclude that caregiving is not exclusively “the activities that are important from a strictly biomedical perspective” (p.181). Similarly, Mundt & Lusch (1997) also believe that “care can be medical and/or non-medical”. Non-medical care comprises of the Activities of Daily Living (ADL) & Instrumental Activities of Daily Living (IADL) (p.58).

To explore the nature of work performed by the home nurses, the present study uses the list of ADL introduced by Bass and Noelker (1987, p.193), which includes carrying out tasks like:

1. Bathing
2. Dressing
3. Grooming
4. Shampooing hair
5. Trimming nails

6. Assisting with walking
7. Transferring from bed and/or chair
8. Toileting
9. Feeding
10. Administering medications
11. Caring for colostomy
12. Caring for catheter
13. Maintaining a special diet

The activities the present research considers as IADL have been drawn from Lawton and Brody (1969), whose list includes actions such as “shopping, food preparation, housekeeping, laundering, use of transportation, and managing finances” (p.185). Besides this, “leisure activities such as going for a walk and reading the newspaper” advocated as IADL by Trydeg (1998, p.23) are also considered by this research as caregiving tasks.

1.9 Care and the Cultural Context

Leininger proposed the ‘Theory of Culture Care Diversity and Universality’, which “focused on the close interrelationships of culture and care the impact on well-being, health, illness, and death” (Leininger, 2002, p.190). This theory addressed the need to provide culture-specific care to assure efficacious nursing services to people. She made the following tenets:

1. Care is the essence of nursing and a distinct, dominant, central, and unifying focus.

2. Culturally based care (caring) is essential for well-being, health, growth, survival, and in facing handicaps or death.
3. Culturally based care is the most comprehensive, holistic, and particularistic means to know, explain, interpret, and predict beneficial congruent care practices.
4. Culturally based caring is essential to curing and healing, as there can be no curing without caring, although caring can occur without curing (Leininger, 2002, p.192).

Culture plays a significant role in people's beliefs and perceptions about health and illness conditions. Leininger's emphasis on incorporating an anthropological view into nursing highlighted the relationship between the two disciplines. She remarked that nurses found it difficult "to discover culture care meanings, practices, and factors influencing care such as religion, politics, economics, worldview, environment, cultural values, history, language, gender, and others. These factors needed to be included for culturally competent care" (Leininger, 2002, p.190).

When the concept 'culturally competent care' is applied to the provision of long-term care in the Indian context, it can be seen that the majority does not favour care in institutional settings. There are many reasons why domiciliary care is preferred to institutionalised care. Providing care and nurturance to its members has been considered one of the key functions of the family. Several scholars have accentuated "the mutual expectations of each generation" about giving and receiving care (Shanas, 1979, p.174). Mehta & Thang (2015) mention that a "cycle of care permeates multigenerational family care" (p.43). Barg et al. (2013) believe that "in Asian culture in general, caregiving is deeply rooted in intergenerational obligations" (p.185). The authors compare American and Hispanic families and explain how different cultures affect their caregiving

practices. It is found that the former use more nursing care services/nursing homes for the care of their loved ones while the others undertake the activities themselves. The “American emphasis on the values of individualism and independence” is contrasted to “cultures that emphasise family and community unity” (p.185).

Brijnath (2012), in her article on urban Indian families, identifies the “continued preference among families for home-based care of elderly relatives” (p. 697). The notion of ‘filial piety’ is regarded as a characteristic of several Asian cultures (Mehta & Thang, 2015). The Indian equivalent ‘*Seva*’ seems to guide people to take care of their parents and other elderly. The authors’ study on the Singaporean society illustrates “a negative attitude toward residential care or the institutionalisation of elders” (Mehta & Thang, 2015, p.49). They note that “for senior Singaporeans, a strong stigma is attached to institutionalisation because it symbolises abandonment by the family. This is inculcated in adult children through socialisation; hence, they are also aware of the elders’ perceptions” (Mehta & Thang, 2015, p.49). Also, several legislative actions are supposed to persuade families’ decisions to get their elderly relatives taken care of at home. For instance, the Indian Government’s Maintenance and Welfare of Parents and Senior Citizens Act 2007 has been cited by many scholars in connection with the aspect mentioned here. Brijnath (2012) contends:

Cultural concepts of care and joint family structures have constructed elder care as critical to family functioning and family cohesion. Such cultural practices are augmented by a legal environment that seeks to locate the primary responsibility of care on families and both reward and penalise families when they do/do not fulfil these responsibilities (p. 698).

The author does not ignore the possibility of the preference for home-based care to change when “forces like rapid economic development, migration, urbanisation and changing family structures deepen their effects on Indian society” (p. 698). Some studies have emphasised governments’ efforts in the form of numerous policies and acts to ensure that the elderly are taken care of by their families. Mehta & Thang (2015) cite the Singapore government’s “Maintenance of Parents Act 1995 as a preventive policy” that safeguards financial support for the elderly by their adult children (p.46).

1.10 Informal and Formal Care

Multiple definitions have been proposed for the concepts of ‘informal care’ and ‘formal care’; the major distinction between the two is that the former is an unpaid activity. Mundt & Lusch (1997) argue that formal care can be provided in different locations such as “the care receiving entity’s home, in a residential community, in the hospital, or a nursing home” (p.58). One of the popular definitions of the concepts is as follows:

In contemporary welfare capitalism, care is provided formally and informally. Informal care involves unpaid assistance provided by intimate partners, family or close friends, or care that is paid but organised without formal authorisation. Formal care is that provided by formally organised and authorised services and generally involves paid labour, although assistance may also be provided by others, including volunteers. (Fine, 2015, p.269).

Though this definition has differentiated the two types of care, some scholars remind us that the complexities involved in this dichotomy should be considered. The following argument clarifies this.

First, we may note that informal caring relations may develop in the process of providing ‘formal’ care (Thomas 1993; Qureshi 1990). Second, it can be argued that often ‘effective’ formal care not only engenders but requires ‘caring about’ emotions. Third, some informal care is provided in an instrumental and calculative spirit. (Bowlby, McKie, Gregory & Macpherson, 2010, p.41).

Writers across the globe highlight women’s “major role in both the formal and informal organisation of care” (Stacey, 2011, pp.43-44). “Additionally, the tasks in both the formal and informal care are often intimate, involving bodywork which can be seen as ‘dirty work’ and of low status” (p.44). It is also recognised that “multiple individuals assist *one another* in their work as caregivers. *Direct help* is given to the older person by helpers (those individuals who are not the primary caregivers), and *assistive help* is extended from helpers to the caregiver” (Sims-Gould, Martin- Matthews, & Rosenthal, 2008, p.68). Therefore, in some cases, the caregivers interact and help each other to care for the patient. Even when the formal caregiver does not directly provide care to the patient but helps the informal caregiver take care of the patient, that activity falls under the umbrella of caring activity. Such care is classified as ‘assistive care’ by several sociologists and care researchers.

In a report on care work published by the International Labour Organization, the authors discern that “care work consists of direct and indirect care activities. Domestic workers, who provide both direct and indirect care in households, are also part of the care workforce” (Addati, Cattaneo, Esquivel & Valarino, 2018, p.xxviii). Researchers also opine that paid care work will become more rampant across societies, and the gendered nature of caregiving will be perpetuated

“as the use of day care and nursing homes expands. Caregiving organisations will become a larger segment of our economy, and women probably will continue to do most paid care work” (Cancian, 2000, p.148).

Hochschild (1983) has extensively worked on ‘emotional labour’, a term she coined to refer to the kind of work performed by those in the service sector. According to her, the commodification of emotion occurs in service professions since specific feeling rules guide the service providers to behave or present themselves in certain ways. “Feeling rules define what we imagine we should and shouldn’t feel and would like to feel over a range of circumstances” (Hochschild, 2003, p.82). Thus, several scholars consider care providers such as nurses also to perform emotional labour. This concept, its significance in the present study, and its critique will be elaborated on later in the thesis.

1.11 Care Network

While discussing care work, the concept of ‘care network’ requires an explanation. Tonkens (2012) finds that it “refers to the circle of people who provide some kind of care or help to the same individual on a regular basis - daily, weekly, or even less often” (pp.203-207). The author explains that “these people can be informal care-givers, unpaid volunteers, or paid professional care-givers” (p.207). She elaborates on “the different types of regimes like the community regime, the welfare-recipient regime, the citizen-consumer regime, and the active citizen regime” (p.201). Under the various regimes, the feeling rules for informal caregivers differ.

To cite the author, “Feeling rules for informal care-givers in the community regime prescribe that they should feel happy and proud to be active in the community and to provide

informal care” (Tonkens, 2012, p.202). On the other hand, in a “welfare-recipient regime, citizens are prescribed generally passive roles, while professional care-givers take over much of what was previously a family or community responsibility” (p.202). This model encourages the cared-for persons not to anticipate much from their kin.

When it comes to “the citizen-consumer regime, care is a commodity. Feeling rules here include not expecting a great deal of unpaid help from close kin, and feeling gratitude when they provide or arrange for care efficiently” (p.202). The active citizenship regime prescribes “citizens to arrange care by themselves, combining their own labor with that of their personal networks (with or without personal budgets) and the professional services” (pp.202-203). She notices that even though this regime is in dominance nowadays, “remnants of other regimes linger on, influencing people’s framing and feeling rules” (p.203).

When the concept of care network and the idea of different regimes are applied to the Indian context in general or the study area in particular, it appears to be a mix of active citizenship and community regimes. A welfare-recipient trend has not been predominant so far. Over the decades, though there has been an increase in the number of people purchasing care services, the idea of providing informal care to one’s close kin is prevalent. The majority of the patients in the country still have their kin as their primary caregivers. In the South Indian state of Kerala, unlike many Western countries, a state-sponsored system/welfare scheme that provides formal healthcare services to chronically ill patients regularly does not exist. In this scenario, the home-based care industry gained prevalence across Kerala. Many people, especially those who are unavailable, incapable, or reluctant to provide care themselves, purchase the services of home nurses for their ailing kin.

Any discussion on the care network would be half-finished without mentioning community care.

1.12 Community Care

The concept of community care is often discussed in connection with geriatric care. It is defined as “help provided to older people in their own homes or within their communities rather than in hospitals or long-term care institutions. This help is provided mainly by their families and supplemented and complemented by local formal services” (Iecovich, 2014, p.25). Another term, aging-in-place, conveys the idea of “remaining at home while ageing and maintaining independence, privacy, safety, competence, and control over one’s environment” (Iecovich, 2014, p.22).

The individuals who deliver varied home care services are known by different names and job titles across regions. While “home attendants”, “home care aides” and “home health aides” are prevalent in the U.S., they “are variously known across Canada as home support workers, personal support workers, community health workers, community healthcare aides, home helpers” (Martin-Matthews & Sims-Gould, 2008, p.69). Home health aides typically possess better training and educational standards than home care aides and personal support workers. Various tasks performed by home health aides and home care aides are discussed in the next chapter.

1.13 The Growing Trend of Home-Based Care

The advances in healthcare technology have aided countless individuals to live longer. Though they suffer from different ailments, many elderly patients like to be provided care in the comfort of their homes. Despite the expansion of elderly residential care homes and assisted living

centres, the majority is being taken care of by their significant others in their own homes (Hanley, Wiener, & Harris, 1991). Not only elderly patients but also people of other age groups who suffer from various chronic ailments and disabilities (who do not require hospitalisation) receive care from their kin. In light of research from different countries, many authors conclude that home care/ community care is a better choice than institutionalised care. Kemper (1992) notes that several elderly choose home care over care in nursing homes, and some perceive the former “as potentially less costly than nursing home care” (p.421). Chichin and Cantor (1992) state that “assisted living in the community is, in many cases, a more humane option than institutionalisation” (p.90). “Family care of an institutionalised relative differed from family care at home primarily in its focus on maintaining family connectedness, hope of recovery, and control over the environment” (Bowers, 1988, p.367). A study about home care in Germany discusses “the principle of home nursing before nursing home” (Seidlein, Buchholz, Salloch & Buchholz, 2020, p.2).

Research also indicates that “formal home care helps the disabled elderly to live independently, to be less burdensome to relatives, and to avoid being cared for in nursing homes” (Hanley, Wiener, & Harris, 1991, p.508). As domiciliary care became popular, a debate among the care researchers concerning formal carers occupying the centre stage took shape. While some researchers argued that formal care would take over home-based care provided by informal caregivers, others stated that informal care would never drop. Supporting the former, Karner (1998) underlines that informal support networks are typically not strong. “Given the current economic situation and changing social trends, some speculate that in the future formal caregivers will replace informal family care providers” (p.69). Conversely, Hanley, Wiener, & Harris (1991) are of the view that “informal social support does not decline with home and community care use”

(p.509). Gupta (2009) also believes that “families will continue to provide care for their elders despite the gradually eroding filial piety norms” (p.1043).

Pyke and Bengtson (1996) explore collectivistic and individualistic systems of families and argue that “collectivists used caregiving to construct family ties, sometimes prompting over care” (p.379). In contrast, “individualists provided less hands-on physical care to frail elderly parents and relied instead on formal supports, such as residential facilities, nursing homes, and hired help” (p.383). Nonetheless, this category did not abandon their ailing kin, but they “managed the finances, made caregiving arrangements and generally maintained regular social contact” (p.383). As per this research, while “feelings of obligation motivated the individualists to provide care, collectivists described caregiving as growing out of attachment to parents” (p.384). This study casts light on individualistic families caring for their relatives due to obligations. A good number of respondents in the present study also consider caring as accountability, which is explained in the chapter on the care recipients. Identical to the individualists in the above account, the families in Kerala who hire caregivers did not want to forsake their parents or ailing kin. Instead, most of them made sure to stay with them in the same household and managed to make the necessary arrangements.

It should not be overlooked that home care is not always preferred to institutionalised care. Research has shown that not all elderly and chronically ill people love to have end-of-life care at their homes. Neither is home care at all times a pleasant experience for the stakeholders involved in the caregiving process. Scholars have elaborated on the deleterious effects of providing home care. It has been discussed how domiciliary care “affects the routines and social interactions of the household members” (Mahmood & Martin-Matthews, 2008, p.23). The authors also clarify why some people do not wish to spend their autumn years at their homes. The reasons for the same are

“absence of informal carers, not wanting to be a ‘burden’ to family and friends, or being against their children delivering them intimate care” (Mahmood & Martin-Matthews, 2008, p.40).

Some works have emphasised that not all clients or their families enjoy a formal care provider’s presence in their homes. For instance, despite the care providers’ support for the cared-for person’s family, Latimer (2011) notes that “the presence of ‘strangers’ was regarded by some as intrusive and compromising of the ideal of ‘home’” (p.40).

1.14 Outsourcing Care

According to Brody, Poulshock, & Masciocchi (1978), a family’s role in the care of an ailing relative depends on several factors like “economic resources, family structure, quality of relationships, and other competing demands on family time and energy” (p.557). Whyte (1997) observes that “with increasing individualism in our society it can no longer be assumed that families will provide the informal network essential to the support of people with complex health needs, nor that the individual would necessarily wish for family support” (p.3). Here, the author recognises the role of formal carers who can assist the patients and their informal carers. The related concepts of direct help and assistive help have already been introduced in the previous section.

When it becomes difficult for the families to deliver care themselves, paid caregivers come to their rescue. Families who can afford the expenses would hire caregivers, and the case in a developing country like India is no different. Migration, urbanisation, and consumerism are the processes that are perceived to have brought this change in Indian society (Brijnath, 2012). She also notes that the “change in women’s roles and their involvement in full-time paid employment

have reduced their availability to care” (p.699). As the ‘Indian joint family’ dismantles, “providing care within familial context appears to be the legitimate way to look after elders”. This has led to “the growth of novel care arrangements such as local care services as an alternative, or complement, to kinship care for elders who stay in India while their kin live abroad” (McKearney & Amrith, 2021, p.10). Nevertheless, many scholars such as Wiles (2003) argue that kin caregivers provide the most support “despite social trends such as female employment and the dispersal of families” (p.189).

The families that outsource care have experienced diverse reactions from different corners; at times, they are frowned upon; if not, their decision is considered wise and economical. Similarly, home-based care has certain advantages and downsides for its recipients. Some authors note that “privatisation takes the form of turning the client or their relatives into employers; this may enable some care users to feel more empowered” (Twigg et al., 2011, p.182). McKearney & Amrith (2021) caution that purchasing care could invite suspicion due to the belief that “care ought to emanate from personal and sentimental concerns, rather than instrumental one” (p.1). Moreover, formal care is regarded as “an invasion of privacy or an encroachment on domestic space” (Angus et al., 2005, p.162).

1.15 Theoretical Framework

The prevailing research findings that stress the relationships between informal and formal caregivers are inconsistent. Here are some of the existing models that describe these associations.

Popularised by Cantor, the Hierarchical Compensatory Model proposes that “the source of assistance follows a pattern based on the primacy or closeness of social relationships, social care

system and explaining the interface between informal and formal caregivers” (Noelker and Bass, 1994, p.357). The model postulates that “each group successively provides assistance due to the unavailability or incapability of a more preferred source” (p.357). Cantor (1991) identifies that the "hierarchical compensatory theory of social supports have kin, particularly spouse and children, preferred as the cornerstone of the support system in most situations, followed next by friends, neighbors, and eventually formal organisations in a well-ordered hierarchical selection process” (p.338).

Edelman and Hughes (1990) advocate a Supplementary Model that recognises that formal services supplement informal care and often provide respite that allows informal caregivers to maintain their caregiving role over time (p. S74). The model “asserts that the primary caregivers are the major helpers and use service providers to augment their efforts or for respite” (Bass & Noelker, 1989, p. S64).

A third model named the Complementary Model combines both models explained above. As per this model, formal care is used “when crucial elements of the informal network are lacking or when there is great need (i.e. greater illness or a disability) and the informal care system is unable to provide the assistance required” (Denton, 1997, p.33).

Another model named the Task Specificity Model is drawn from the work of Litwak (1985). As the name suggests, the two categories of carers perform entirely different tasks. The model discusses “a division of tasks by informal and formal caregivers based on the characteristics of each group” (Denton, 1997, p.31). Otherwise referred to as the Dual Specialisation Model, it

ascertains formal caregivers to be better able to perform technical tasks and nursing care while the informal carers carry out mundane activities like ADL (Litwak, 1985, p.322).

Unlike the above models, Greene (1983) put forth a Substitution Model that suggests formal caregivers replacing informal caregiving. The author's study results "indicate a substantial tendency for formally provided care to be substituted for informal" (p.609). Hanley, Wiener, & Harris (1991) believe that formal care can provide informal caregivers "a needed respite and allow them to arrange their hours and tasks more efficiently" (p.517). However, most of the studies that examined these models found that substitution does not happen in a true sense. Denton's (1997) study showed support for the complementary model.

Sims- Gould and Martin-Matthews (2010) developed the below conceptual model (Figure 1.1) to demonstrate the interactive nature of caregiving (p.415). This model has been adapted and modified to suit the present study. This framework will guide the research in examining the relationships between the two types of caregivers. (Refer to Figure 1.2).

Figure 1.1: Contributions in Caregiving (Sims-Gould & Martin-Matthews, 2010, p.417)

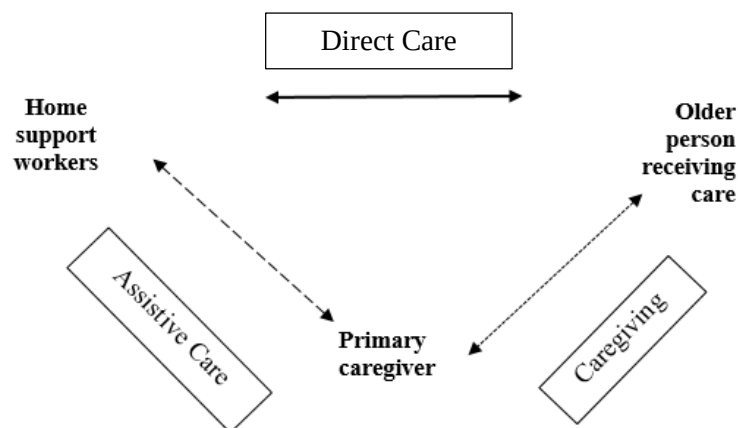
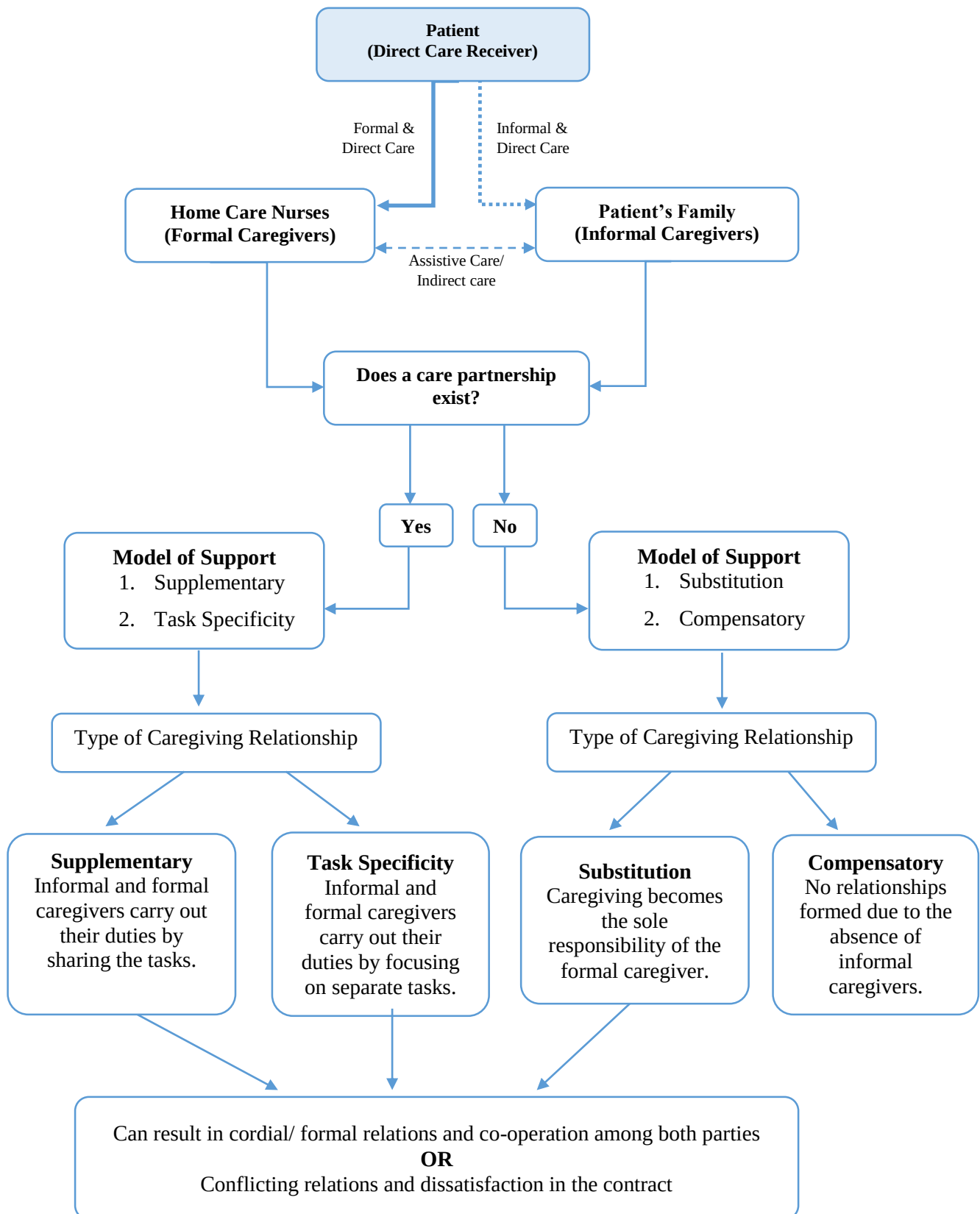


Figure 1.2: A proposed theoretical framework on caring relationships and partnerships in home-based care



Besides the above theoretical framework, this study uses a set of theories on care work that discourse the nature of work performed by caregivers and their perceptions about the same. How each of these frameworks applies to the cases of the home nurses is presented in Chapter 2 discussion section.

1.16 Significance of the Study

The literature survey suggests that the Indian state Kerala has been a leading supplier of nursing care services in the international market (Abraham, 2004; Nair, 2012; Percot, 2006; Walton-Roberts, 2012; Walton Roberts & Rajan, 2013). However, most of the nursing research on Kerala has focused on clinic-based care. Not many entries have concentrated on privately purchased domiciliary care though there are sufficient works on palliative care and care in nursing homes. While clinic-based care is not required for patients who suffer from acute illnesses or chronic and terminal illnesses, their homes become the site of care. In such instances, they use professional help provided by carers known across Kerala as ‘Home Nurses’.

In Kerala, ‘home nursing’ (as home-based nursing is known in the state) has been in vogue for a few decades now. The caregivers either reside with the patients (clients) or visit their homes to deliver their services. Though recent research by George & Bhatti (2019) has deliberated on challenges facing male nurses in Kerala, no scholarly effort has been made to map the lives of people involved in domiciliary care. Analysing the studies on nursing in Kerala also reveals a dearth of themes such as relationships between the stakeholders involved in the caregiving process. The belief that in-depth studies on domiciliary care and the lives of live-in caregivers (hereafter

‘home nurses’) could subside this dearth encouraged the researcher to embark on the study using an anthropological perspective. The study has been titled “The Caring ‘Other’: Dimensions of Home-based Nursing in Kerala, India”.

Anchored on the theoretical framework, the study investigated various stakeholders in the home-based care sector in Kerala and their roles in the caregiving process; the nature of relationships between these categories; the satisfaction levels concerning the services rendered and received; and the challenges and tensions involved in forming a care partnership.

1.17 Objectives

- 1) To analyse the home nurses’ socio-economic and educational backgrounds and look into their prior work experiences.
- 2) To examine the training imparted to the nurses by the nursing agencies, explore their recruitment strategy, and identify their role in the domiciliary care sector.
- 3) To understand the care receivers’ reasons for hiring the home nurses and analyse the selection criteria adopted by them.
- 4) To identify various tasks performed by the home nurses, their roles in the patients’ therapy management and examine the task segregation between formal and informal caregivers.

- 5) To assess the caregivers' relationships with clients and their families and understand the nurses' challenges at work.

1.18 Methodology

The nature of the study is predominantly qualitative. The data collection took place during May 2018 and July 2019. The region chosen for the study was Southern Kerala, where domiciliary care is more prevalent than the state's northern part. The districts selected include *Thiruvananthapuram, Kollam, Pathanamthitta, Alappuzha, Kottayam* and *Ernakulam*. In-depth interviews of the three groups of informants, viz. the caregivers, owners of home nursing agencies that facilitate the services, and clients who purchase the services, were conducted using semi-structured schedules. Most of the interviews lasted approximately an hour, though some were extended based on the interviewees' convenience. A few respondents were initially asked the consent to record the interviews, but they denied it. Therefore, none of the interviews was audio-recorded to avoid the participants misinterpreting that the researcher would cause them some harm.

In most cases, the home nursing agencies became the sampling frame as they helped identify the other two categories. These agencies could be identified with the help of advertisements in newspapers and information available on the internet. The owners of the agencies were interviewed to collect the required data regarding their respective enterprises. In cases where the owners were absent, the office staff concerned were interviewed. The participants who constituted the category of care providers were scattered as they were employed in different households across the districts in the study area. However, many care providers were interviewed

at the nursing agency offices. This was possible since they visited the offices when the researcher was present there. In other cases, the caregivers were interviewed at their workplaces (houses of service receivers) or their own homes. The care providers who became the respondents were randomly chosen when many of them were present in the nursing agencies at a time. Some respondents also referred to a few of their co-workers who could be potential respondents. This happened especially in the cases of male caregivers as they are a minority in the sector. A couple of nursing agencies did not employ male care providers at all. Thus, the few men who could be identified enlisted more people from their contacts.

To find respondents for the category of service receivers/ clients, the researcher had to randomly choose some from the list available with some nursing agencies. Whenever possible, it was tried to adopt a random sampling technique. Nonetheless, throughout the data collection phase of the study, the snowball technique was used in some form or the other. The method was adopted to reach a desirable sample size for each of the three categories involved. Efforts were made to ensure that the sample was representative of characteristics such as age and gender. Further details about the sample are provided in the following chapters.

The interviews were carried out in Malayalam, the regional language. The anonymity of the respondents was assured, and their informed consent was sought. Though the interview schedules were in English, they had to be translated to Malayalam for the informants' ease of responding. The English schedules for all three categories are attached in the Appendix section.

1.19 Ethical Considerations

The research was approved by the University of Hyderabad's Institutional Ethics Committee. The certificate to conduct the research was granted on 09/03/2018 for Application No. UH/IEC/2018/6. The informants were conveyed that their participation in the study was voluntary, they could withdraw from it any time, and their identities would be masked to ensure confidentiality and anonymity. Therefore, pseudonyms have been used in the case studies and narratives presented throughout the thesis.

1.20 Limitations of the Study

Like any other research, this study also has certain limitations. Anthropological fieldwork involving participant observation could not be conducted for this research as the participants were spread out in different parts of the study area. Moreover, staying with the caregivers and gaining a first-hand experience of the nature of their work was not feasible since they themselves stayed like guests in the homes of their employers. Since they are all scattered and located in different regions, all three groups of respondents could not be engaged in a group discussion. Even in cases where the caregivers were present at their workplaces, they were not interviewed in their employers' presence. They required privacy to answer several questions, particularly those related to the nature of relationships with the employers and the problems they faced in the latter's house. Considering that fact, the care providers and care receivers were interviewed separately. However, that also seems to be an inadequacy since interviewing all three categories together would have resulted in looking at the characteristics of the home-based care sector in Kerala from a different

perspective. Another shortcoming of the study is that male respondents from the category of caregivers were significantly less in number. Among the 150 caregivers interviewed, only 20 were male. These numbers echo the gender composition in the field and affirm the shortage of male caregivers. Yet, a greater number of men would have strengthened the understanding of the cases of male caregivers.

Home care clients numbered close to half of the caregivers. Though more than 100 prospective respondents were approached, almost a quarter denied cooperating or had some inconveniences participating in the study. Due to time and budget constraints, the sample of this category scattered across the chosen districts was limited to 76. This disproportionate number of caregivers and care receivers and the inability to include caregivers associated with each care receiver are limitations. Also, since the interviews could not be tape-recorded, the researcher might have missed capturing some details of the conversations.

However, despite these limitations, the data gathered could provide insights into the home-based caregiving in the study area. Exploring the various stakeholders in the industry helped the researcher apprehend the lives and work of the home nurses, the relationships involved in the caregiving process, and identify the associated nuances. The data obtained not only attempts to address the objectives framed but also substantiates the theoretical perspective adopted in the study.

1.21 Chapter Scheme

Vis-à-vis each objective, the data collected and analysed have been organised into six chapters.

Chapter 1, titled ‘Introduction’, consists of descriptions of the significant concepts the study revolves around, their operational definitions, a review of the existing literature, notes on the theoretical framework, objectives of the research, and the methodology adopted for data collection. The chapter specifically looks at the concepts of ‘care’ and ‘care work’ to shed light on the significance of care in the profession of nursing. The alliance between Anthropology and Nursing is also analysed.

Chapter 2, titled ‘Home Nurses: Profiling the In-Home Care Providers in Kerala’, discusses the socio-demographics of these caregivers. The work profile of the nurses is explained. Their perception of caregiving, their reasons and motivations to enter the field, and their prior work experiences are also presented with the help of a few case studies. Their perceived role in the therapy management of the patients they cared for is also included.

Chapter 3, titled ‘Home Nursing Agencies: Facilitators of the Care Services’, looks at the role of nursing agencies as mediators in the care industry. The home-care industry in Kerala is introduced, and the growing trend of home-care is elaborated. Besides this, other aspects concerning the industry such as recruitment, training, and retention of staff are also explored. The

agency's perception of caregiving and their various rules and restrictions for home nurses and clients are discussed.

Chapter 4, titled 'When Care Gets Commodified: Analysing The Perspective of Service Receivers', presents the reasons why the services of home nurses were sought and the selection criteria employed to hire them. An effort is also made to identify if any referrals were made with regard to choosing the caregivers. The care receivers' perception of caregiving, their experiences with the in-home care providers, their opinions and remarks about them, and their idea on the characteristics of an ideal caregiver are also included.

Chapter 5, titled 'When Caregivers and Care Receivers Interact: Relationships, Tensions and Challenges', explores the nature of relationships between the two categories of caregivers besides that between the home nurses and patients. The emotional bonds that exist between some home nurses and patients are depicted with the help of a few case studies. Notes on the agency's interactions with the other two sections of study participants, viz. the care providers and care receivers, are presented. An attempt is made to explore the care receivers' and caregivers' perceptions of ideal relationships and compare them with the existing relationships, as explained by both the categories. This chapter also looks at the task segregation between formal and informal caregivers. An explanation of various difficulties the caregivers face in their work is also presented.

Chapter 6 is the final chapter which provides a conclusion and summary of the study findings and analyses.

Chapter 2

Home Nurses: Profiling the In-Home Care Providers in Kerala

2.1 Introduction

‘Home nursing’ has gained currency in Kerala over the last few decades. The caregivers employed in the private home-based care sector were labelled as ‘home nurses’ when their vocation became ‘home nursing’. The opportunities for nursing at home for various reasons is a newfound employment opportunity for certain women and men and at the same time a challenge for their role performance as ‘nurse’. Since the employment of home nurses is generally through some agencies, and their roles are to be enacted in a ‘family’ environment, the role sets of the home nurses are qualitatively different from the clinic-based nurses. These home nurses may not be entirely professional, and their job charts also need not be limited to the ‘nursing’ work. Their working hours may be longer as they are live-in caregivers who ensure round-the-clock services to their clients. The expected nature of care may considerably differ depending on whom they serve - geriatric care, postnatal care, post-surgery care, or others.

When the changing family structure and the consequent inter-generational strife had an adverse effect on the physical and mental health of the older people across the state, these home nurses have become a helping hand for several of them. At times, the entire responsibility of providing care and affection for the patients is vested in their hands. Despite caregiving being the primary task assigned to the home nurses, many provide housekeeping support to the clients based on requirements. In addition to looking after the ailing elderly, these people help the patients’

informal caregivers (primary kin), thereby working as home nurses-cum-maids. Such people have been instrumental in reducing the burden and stress of women, especially working women who find it difficult to manage household chores and formal employment.

This chapter aims at detailed profiling of the Home Nurses based on the sample chosen for the study. The findings of this chapter begin with an analysis of the socio-demographic characteristics of the caregivers. The nature of work performed by the home nurses is explained, details such as their reasons and motivations to enter the field, their prior work experiences, and perception of caregiving are presented with the help of a few case studies. In the discussion section, the existing theories of care work have been examined in light of the findings presented in this chapter.

The terms ‘caregiver’, ‘care provider’, and ‘HN’, the shortened version of ‘Home Nurse’, have been used throughout the thesis to refer to the in-home care providers. In this chapter, they are also referred to as respondents or informants. The patients are termed as clients and the patients’ families as clients’ families or employers. The findings of the study are discussed in the following sections.

2.2 Socio-demographic Profile of the Care Providers

2.2.1 Gender and Age

The data for the study was collected from 150 care providers, out of which about 87% were females. The care providers belong to different age groups ($M = 48.66$, $S. D = 36.06$) and their ages range from 22 to 73 years. These care providers have been grouped into categories, and their distribution based on age is presented in Table 2.3. Among the twenty male caregivers, the

youngest is aged 32, while the eldest is 70. The mean age of female care providers is 48.76 (*S. D*= 11.40), while that of male care providers is 48.05 (*S. D*= 11.44).

It is evident from Table 2.3 that the highest number of care providers belong to the category 51-60 years old. The class 41-50 years also has a comparable number, and both categories jointly account for more than half of the sample.

2.2.2 Marital Status

As observed, female caregivers make up the majority of the sample. Among these women, a considerable number (48.67%) are widows and divorcees. Only 13 respondents are unmarried, and six out of them are men. The gender and age compositions of the sample depict that the greatest number of respondents are aged between 40 and 60. Women being the majority of this category, and widowed or divorced women making up a significant part of the same, it is believed that the numbers reflect their liberty in choosing their occupation. The freedom to make decisions related to work owing to the absence of a spouse is one possible explanation for their numerical dominance in the sample.

2.2.3 Religion and Caste

When the religious affiliations of the care providers are considered, the majority is adhering to Hinduism. Almost a quarter of the sample believes in Christianity. Only 5.33% of the sample belongs to the Muslim community. This could be attributed to two reasons: Muslims in the study area, in particular, and Muslims, in general (as highlighted by several other studies) are not much involved in caregiving professions such as nursing. The second reason is the religious composition

of the study area. The districts selected for the study are from Southern and Central Kerala, which are not Muslim majority areas. Compared to Northern Kerala or the Malabar region, the Muslim population is lesser in the study area, and this could have been reflected in the negligible number of respondents from this community.

An attempt was made to understand the castes of the care providers. The majority did not reveal their caste affiliations. It is assumed that a good number of such respondents belong to castes lower in the hierarchy. They might have hidden their caste identities due to the apprehension of not being chosen by certain clients or being discriminated against by caste. The information provided by the nursing agency owners (presented in Chapter 4) supports this assumption. It was observed that some of the respondents who belong to a higher caste (Nair) were keen about mentioning their castes. Also, a few of them expressed their helplessness and explained their poor economic background and familial situations that brought them into this job where they have to deal with polluting substances such as the patients' excrements. These respondents made it clear that they would not have chosen this profession if not for their financial difficulties. They are aware of the stigma attached to this profession and believe that caregiving is not a job meant for upper caste people like them.

2.2.4 Educational Qualification

Upon analyzing the educational qualifications of the caregivers, it was identified that 60.67% had gained formal education below Class X. Among these people, one-fifth have completed only their primary education. Though about a third of the total sample has secured higher secondary education, degree holders comprise a meagre 7.33%. This reveals that the majority of the HNs do not possess high educational qualifications. The mean years of schooling are 8.3 years (*S.D.* = 3.49). The male caregivers seem to be slightly better educated than their

female counterparts. The former has an average education of 10.2 years (*S.D.* =2.26), whereas the latter has an average of 8 years (*S.D.* = 3.56). This trend casts light on gender discrimination in education and the ‘economic’ compulsions for male members to accept underemployment.

A Pearson’s correlation was conducted to identify if there exists any relationship between the age of the caregivers and their educational attainment. The results revealed that the variables are negatively correlated. More the age, lesser the educational standards. The correlation is moderate ($r = -0.469$). The results exported from SPSS are demonstrated in the table below.

Table 2.1: Correlation between caregivers’ age and their education

Correlations		Age	Education years of schooling
Age	Pearson Correlation	1	-.469**
	Sig. (2-tailed)		.000
	N	150	150
Education in years of schooling	Pearson Correlation	-.469**	1
	Sig. (2-tailed)	.000	
	N	150	150

**. Correlation is significant at the 0.01 level (2-tailed).

2.2.5 Economic Status of the Caregivers’ Families

The majority of the informants had their earnings as the only source of income for their families. This is so because, as already stated, a substantial percentage of them are widowed or divorced. Less than one-fourth reported having double income as their spouses are also working. Some female caregivers informed that their spouses are not employed either due to ill health

(10.67%) or alcohol addiction (2%). Out of the 13 married male respondents, the spouses of only three are formally employed. From what has been reported, it is evident that the majority of the care providers belong to poor economic status. Many respondents mentioned that they are in debt as they have taken loans for various purposes, including their children's marriage and education. Table 2.4 highlights the employment statuses of the caregivers' spouses.

Though it is not assured that all the care providers will be employed throughout the year, most of them revealed that they find work almost every month. Close to two-thirds of the caregivers are paid between 12,000 and 15,000 rupees a month. The earnings of 6% of the sample are less than 10,000 rupees since they work part-time. Another 6% earn between 18,000 and 20,000 rupees a month. Only five respondents (3.33%) reported earning rupees 20,000 or more monthly. Most of the people who are paid the highest are involved in postnatal care. The average monthly salary of the sample is 14,613 rupees ($S.D.= 2708$). Regarding gender-wise averages, male caregivers have a mean monthly income of rupees 16,775 ($S.D.=472$) while female caregivers have a mean of rupees 14,280 ($S.D.= 2758$). The variations in salaries based on various criteria (such as the care provider's gender, nature of work performed and patient's gender) are discussed in relevant sections later in this chapter and the subsequent chapters.

A regression analysis was carried out to identify the factors that impact the caregivers' salaries. It was found that there is a significant impact of gender, age, involvement in postnatal care, and receipt of nursing training on the caregivers' salary ($R^2=.459$). This means that the variables gender, age, involvement in postnatal care, and receipt of nursing training account for 45.9% of the variability in salary. The analysis results exported from SPSS are given in the table below.

Table 2.2: Regression analysis showing variables that impact the caregivers' salary

Variables Entered/Removed ^a			
Model	Variables Entered	Variables Removed	Method
1	Receipt of nursing training, Gender, Involvement in postnatal care ^b	.	Enter

a. Dependent Variable: Log of salary

b. All requested variables entered.

Model Summary				
Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.678 ^a	.459	.448	.05998088975453

a. Predictors: (Constant), Receipt of nursing training, Gender, Involvement in postnatal care

ANOVA ^a						
Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	.44	3	.149	41.322	.000 ^b
	Residual	.525	14	.004		
	Total	.971	149			

a. Dependent Variable: Log of salary

b. Predictors: (Constant), Receipt of nursing training, Gender, Involvement in postnatal care

		Coefficients ^a				
		Unstandardized Coefficients		Standardized Coefficients		
Model		B	Std. Error	Beta	t	Sig.
1	(Constant)	4.410	.025		174.134	.000
	Gender	-.098	.015	-.415	-6.726	.000
	Involvement in postnatal care	-.150	.015	-.07	-9.735	.000
	Receipt of nursing training	-.042	.014	-.183	-2.968	.004

a. Dependent Variable: Log of salary

2.3 Work Experience

The respondents' experience in caregiving ranges from less than a year to more than 20 years. The average work experience is 7.61 years ($S.D. = 6.57$). More than half of the sample (55.34%) had work experience greater than five years. Almost one-third of the sample is relatively new to the home care industry and have fewer than three years of experience. The average experience of male caregivers and female caregivers is more or less the same. It is 7.65 years ($S.D. = 4.77$) for the former and 7.6 years ($S.D. = 6.82$) for the latter.

It was identified that better-qualified people are less likely to have the caregiving profession as their first occupational choice, due to which they have less experience in the field. Data reveal that all 11 degree holders have less than ten years of experience. Out of these people, six have been working for less than three years. Academic nursing qualified informants who had worked as staff nurses in private hospitals were dissatisfied with the pay and work conditions. Though some of them realize that clinic-based nursing has better dignity and status, they took up home-based care, not as a career option but as a stop-gap arrangement.

2.4 Part-time Workers

One-tenth of the sample work part-time. They are live-out caregivers from local areas who work from morning till evening. All the 15 who work part-time are women, and nine of them earned less than 10000 rupees a month. Among the others, two women earned between 18000 to 20000 rupees a month, and one woman reported the job fetching her more than 25000 monthly. These women who got paid more than 18000 rupees are involved in postnatal care. Nine people preferred part-time to full-time work as they had personal reasons that limited them to stay away from homes. Some of them had young girl children or ailing family members. Five women chose to work part-time since they did not want to stay in clients' homes. It was not just out of fear, but

they considered it immodest to stay in strange places. The remaining one person had some health issues that stopped her from being a full-time care provider.

Table 2.3: Socio-demographic characteristics of the caregivers (n=150)

Sl. No	Characteristic	Numbers and Percentages (in parentheses)	Mean & SD (where applicable)
1.	Gender		
	Female	130 (86.67)	
	Male	20(13.33)	
2.	Age		
	Less than 25	2 (1.33)	Mean Age = 48.66, S. D = 36.06
	25-30	7 (4.67)	
	31-40	28 (18.67)	Mean Age of women= 48.76, S. D= 11.40
	41-50	42 (28.0)	
	51-60	46 (30.67)	
	61-70	24 (16.0)	
	Above 70	1 (0.67)	Mean Age of men= 48.05, S.D= 11.44
3.	Religion		
	Hindu	104 (69.33)	
	Christian	37 (24.67)	
	Muslim	8 (5.33)	
	Tribe	1 (0.67)	

4.	Caste/ Community		
	Hindu, Nair	16 (10.67)	
	Hindu, Ezhava	8 (5.33)	
	Scheduled Caste	9 (6)	
	Scheduled Tribe	1 (0.67)	
	Latin Catholic	16 (10.67)	
	Roman Catholic	1 (0.67)	
	Jacobite	2 (1.33)	
	Caste not applicable (Muslim)	8 (5.33)	
	Caste not revealed	89 (59.33)	
5.	Education (Years of Schooling)		Mean Years of Schooling= 8.3 S.D.= 3.49 Female Average= 8 S.D. = 3.56 Male Average= 10.2 S.D. = 2.26
	Below 5 years	39 (20.67)	
	6 to 10 years	52 (40)	
	11 to 12 years	48 (32)	
	Above 12 years (Degree holders)	11 (7.33)	
6.	Work Experience (in years)		Average experience Mean= 7.61 S.D. = 6.57 Female Average= 7.6 S.D. = 6.82 Male Average= 7.65 S.D. = 4.77
	Less than a year	17 (11.33)	
	1 to 3 years	28 (18.67)	
	4 to 5 years	22 (14.67)	
	6 to 10 years	42 (28)	
	11 to 15 years	22 (14.67)	
	16 to 20 years	15 (10)	
	21 years or above	4 (2.67)	
7.	Marital Status		
	Married	64 (42.67)	

	Divorcee	19 (12.67)	
	Widow/ Widower	54 (36)	
	Unmarried	13 (8.67)	
8.	Monthly Income		Average Salary= 14,613 S.D.= 2708 Male- Mean= 16,775 S.D. =472 Female- Mean= 14,280 S.D. =2758 Difference between average salaries= 2495
	Less than 10000	9 (6)	
	10000-12000	4 (2.67)	
	12000-15000	94 (62.67)	
	15000-18000	29 (19.33)	
	18000-20000	9 (6)	
	20000-25000	4 (2.67)	
	More than 25000	1 (0.67)	

Table 2.4: Occupational statuses of caregivers' spouses

Employment Status	Numbers and Percentages (in parentheses)
Employed Spouses	
Husband employed	32 (21.33)
Wife employed	1 (0.67)
Wife employed as a Home Nurse	2 (1.33)
Unemployed Spouses	
Husband is a drunkard and does not earn	3 (2)
Husband is unemployed due to illness	16 (10.67)
Wife is unemployed	10 (6.67)
No Spouses	
Widowed/ divorced/ unmarried	86 (57.33)

2.5 Past Struggles and Seized Opportunities: Employment Histories of the HNs

Most of the respondents were involved in different occupations before entering the caregiving industry. For 16%, the role of care providers was their first paid job. There is no single occupation that the majority was associated with. Most of the respondents were working in the unorganized sector. The highest number of respondents (18%) worked as daily wage labourers. While about 15% were staff at retail shops, almost an equal number used to be employed at cashew factories. It should be noted that only one-tenth of the sample have had prior experience working in hospitals. Out of these people, only five were nurses employed in hospitals. The rest had worked as janitors, attenders or assistants and learnt some healthcare tasks from their work settings by observation. The varied occupational backgrounds of the care providers reveal that the majority did not have any experience carrying out caregiving tasks requiring medical/ nursing knowledge.

2.5.1 Reasons to Give Up the Previous Job

There are several reasons why the informants left their previous jobs and chose to become care providers. More than one-third find their present job a better-paying one. While about a quarter had unfavourable working conditions in their previous occupations, less than 15% could not continue their past employment due to health issues. Adverse work conditions include long work hours, problems at the workplace, and night shifts (in the cases of hospital nurses). Less than one-fifth of the informants found their earlier jobs challenging since they had to do physical labour that used to cause them bodily discomfort. This reason was mainly cited by those who were construction workers and daily wage labourers earlier.

Table 2.5: Employment histories of the caregivers (n=150)

Sl. No	Characteristic	Numbers and Percentages (in parentheses)
1.	Previous occupations	
	None	24 (16)
	Hospital nurse	5 (3.33)
	Hospital staff	10 (6.67)
	Cashew factory worker	20 (13.33)
	House maid/ domestic help	16 (10.67)
	Staff at a retail shop	22 (14.67)
	Hotel worker	11 (7.33)
	Construction worker	7 (4.67)
	NREGA worker	4 (2.67)
	Daily wage labourer	27 (18)
	Other jobs like teaching	4 (2.67)
2.	Reasons to leave previous jobs	
	Dissatisfied with the pay	52 (34.67)
	The difficulty of the job	12 (8)
	Unfavourable working conditions	36 (24)
	Health issues	20 (13.33)
	Other	6 (4)
	N.A. since no job earlier	24 (16)

2.6 Entry to Home Based Nursing: How and Why

2.6.1 Association with Nursing Agencies

The majority of the care providers were associated with nursing agencies and thus sought employment via these mediators. About 9% of the sample are directly employed by the clients,

and in most cases, they are referred by some relatives/ acquaintances of the clients. Some of these care providers who are directly hired were previously associated with nursing agencies. They argue that they do not find any point in having a middleman since a fixed amount from their monthly salaries goes to the agencies. Once these caregivers formed good relationships with their clients and established some connections, they thought of breaking their link with the agencies to save some 2000-3000 rupees monthly. Several others who are against the idea of agencies collecting their commission continue to be associated with them. They believe that the agency owners try their best to ensure safety at the clients' homes. An informant says, "even if some dispute arises with a client's family, the agency will make all efforts to save the caregiver if they are innocent".

2.6.2 Academic Nursing Background

As far as the care providers' academic nursing background is concerned, more than 85% of the sample have had no connection with nursing before entering the field. Among the others, only seven are academic nursing qualified. The remaining have obtained some training concerning nursing procedures. The nursing qualified caregivers' reasons for entering the home-based care industry by leaving work at clinics/ hospitals and their satisfaction in the current job are elaborated in the sections below. The differences they find between both types of nursing have been discussed with the help of a few case studies.

2.6.3 Reasons to Engage in Home-Based Care

The respondents chose to take up the role of care providers due to varied reasons. While it was financial reasons that prompted half of the sample, about one-fifth had personal reasons along with financial ones. These personal reasons include concerns like bitter relationships with their

family members. Almost a quarter cited interest in looking after the patients and financial considerations as the motive behind taking up caregiving. Only 4.67% opined that they are in the job solely due to their interest in caregiving. These people believe that it is a divine activity to look after the ailing, and for them, the satisfaction earned from work is more rewarding than the monetary benefits.

It was mentioned by a section of care providers that they do not like to go home even during those days when they can take leave. This is especially the case with several HNs who have married children who exploit them and snatch a share of their hard-earned money. Some home nurses aged above 60 years revealed that they do the work despite their ill health as they lack family backing. Some are particular that they should earn for themselves, as long as their minds and bodies support them to work.

Many female informants were interested in continuing in the sector since it fetched them better income than their previous jobs. In the cases of caregivers who are widows and divorcees, the entire responsibility of their family and children is on their shoulders. Some women chose the job to pay off the debts created due to spending for their children's marriage and education or their parents' healthcare. While the widowed and/or childless women use the job to escape their loneliness and boredom, some do not want to become a burden for their married children. Also, those women who face violence at home, particularly from their husbands, consider the job a rescue from their threatening family life. Since they have a roof over their head and food to eat at the clients' homes, almost all the employees are happy about that aspect.

As the following case illustrates, the job has provided psychological respite besides giving financial aid to several caregivers.

Case - 01

Ponnamma, one of the oldest among the informants, is 73 years old. She works as a postnatal care provider and has around two decades of experience. She does not have any health concerns other than minor issues, like joint pains and body aches. Being a widow who has unpleasant relationships with her married adult children, her personal life has been miserable. Before becoming a caregiver, she was not involved in any paid job. Once she faced economic hardships, she had no other way but to start working. She says that her daughter is responsible for her plight, though she was good to her. She recalls donating her daughter a kidney when she faced kidney failure. Ponnamma adds, “I was there to help them whenever they required some support emotionally. When I needed some financial assistance, nobody really wanted to help me. I do not wish to burden them either. Now that I have this job, I earn enough to sustain my life. Sometimes when I get my salary, I buy some goodies for my grandchildren”. Ponnamma’s case discloses that financial conditions and bitter family relations demand some caregivers to continue working despite their old age.

2.7 Nursing as Women’s Forte

Taking clues from the literature survey, an attempt was made to understand if the respondents considered nursing a job suitable for women due to their gender roles and the ease of performing it. The question was posed only to the female caregivers, and it was found that all the respondents except one replied in the affirmative. One respondent states, “I am glad that I chose a job meant for women. These days some men have also taken up nursing. But, I think it does not suit them much because it needs much patience to bear with the sick, and only women (particularly mothers) can do it properly”. Another one remarks, “I have taken care of my children and my

elderly parents whenever they fell sick. Women can empathize with a patient, adjust to their temperaments and behave affectionately with ease. I continue to be in this field because I enjoy what I do”. An informant named *Sheeja* says, “When I registered at the home nursing agency, I knew that the job is not going to be difficult. Women do not need any training to take care of sick people, except to carry out nursing procedures. We have been doing it at our homes ever since we became matured”. Those involved in postnatal care hold the view that they are performing a job that is earmarked for women. One of them stated, “Caregiving, in general, is something that requires a knack which women naturally possess. And, we are doing a work that men can never do”.

A similar question was posed to the male respondents, and the results of the same are explained in the section on male caregivers.

2.8 Experience as Home Nurses: Ease and Contentment

2.8.1 The Difficulty of the Job

The respondents had to rate the difficulty level of the job on a scale of 1 to 5 (1 being very easy and 5 very difficult). Half of the sample considers their work easy to carry out, while around one-third find it moderately easy. It is worth noting that none of the informants rated their job as very difficult. As expressed by several caregivers, the main reason for experiencing difficulty is the demanding task of dealing with heavy patients, thereby revealing that the patient’s physique impacts the caregiver’s ease of doing the job. Especially those care providers who are either above 50 years or not very healthy find it hard to handle hefty patients. Some informants opined that they prefer bedded patients to elderly patients who are ambulant. They find that the work is less in the former, especially patients on urinary catheter and tube feed do not require the caregivers to

perform much tiring work. In comparison, elderly patients who are not confined to bed have to be lifted often and taken for bathing, toileting, and sometimes require assistance with eating. Therefore, the nature of the patient's illness also influences the difficulty level of the caregiver's work.

As revealed by some informants, the ease of the work also depends on the place where they get employed, the nature of relationships with the clients, the patient's illness condition and state of mind. A few pointed out that stubborn and mentally ill patients who become agitated are risky.

2.8.2 Job Satisfaction

The respondents rated the satisfaction level of the job on a scale of 1 to 5 (1 being least satisfied and 5 most satisfied). None of the respondents indicated that they were highly dissatisfied with their work. While 6% were dissatisfied, less than 15% were moderately satisfied in the profession. More than two-thirds were satisfied with their work. Close to 10% rated they were very satisfied in their roles as in-home caregivers. The respondents' major sources of satisfaction were the happiness of serving the ailing elderly, seeing the clients and families express contentment with their services, and developing good bonds with their clients.

The following case exemplifies the sources of satisfaction for the caregivers.

Case - 02

Saleena is a 32-year-old Muslim woman who has been a home nurse for about two years. She is a divorcee who has two children of school-going age. Since she has to be away from home, both children stay in a hostel run by a religious institution. Earlier she worked as a labourer dependent on daily wages, a lottery ticket seller, and a sales staff. Though all her relatives are

aware of her present occupation, most of them are not supportive. Saleena does not bother about their backing as she is the family's sole breadwinner, and her priority is her children's education. She admits that her earnings are better now than what she used to earn from her previous jobs.

In these two years of experience, she has learnt almost all essential healthcare tasks, like administering insulin, feeding the patient through a Ryle's tube, checking blood sugar levels, wound dressing, and catheter care. She has cared for patients who have chronic ailments and are bedridden due to old age or paralysis. She has been with the client's families that follow different religious faiths but reports that they never maltreated her though they enquired about her religious and family backgrounds. What makes her content mainly is that the clients' families have been gentle in their relationships, and some elderly patients treated her like a child. She recalls that some families involved her in their family functions. She feels recognised when the patients' families give significance to her opinions relating to the health care choices. She does not forget to acknowledge the clients' primary caregivers, who offered her the requisite support to perform all tasks optimally.

A Pearson's correlation was conducted to find out the relationship between job satisfaction and the perceived difficulty of the job. The variables are found to be negatively correlated. Greater the difficulty, the lesser the satisfaction. The correlation is strong ($r = -0.688$). The results are demonstrated in the table below.

Table 2.6: Correlation of job satisfaction and perceived difficulty of the job

Correlations		Satisfaction	Difficulty level of the Job
Satisfaction	Pearson Correlation	1	-.688**
	Sig. (2-tailed)		.000
	N	150	150
Difficulty level of the Job	Pearson Correlation	-.688**	1
	Sig. (2-tailed)	.000	
	N	150	150

** . Correlation is significant at the 0.01 level (2-tailed).

Table 2.7: Employment details of the caregivers (n=150)

Sl. No	Characteristic	Numbers and Percentages (in parentheses)
1.	Registered in Nursing Agency	
	Yes	137 (91.33)
	No	13 (8.67)
2.	Nursing Background	
	Nursing degree/ diploma	7 (4.67)
	Nursing training	15 (10)
	No background	128 (85.33)
3.	Reasons for Taking Up the Job	
	Financial	76 (50.67)
	Financial + personal	27 (18)
	Health issues in the previous job	2 (1.33)
	Financial + Interest to take care of patients	34 (22.67)

	Interest to take care of patients	7 (4.67)
	Ease of the job	3 (2)
	Other	1 (0.67)
4.	The Difficulty Level of the Caregiving Work	
	Very Easy	7 (4.67)
	Easy	76 (50.67)
	Moderately easy	51 (34)
	Difficult	16 (10.67)
	Very Difficult	0 (0)
5.	Job Satisfaction	
	Very dissatisfied	0 (0)
	Dissatisfied	9 (6)
	Moderately satisfied	21 (14)
	Satisfied	107 (71.33)
	Very satisfied	14 (9.33)

2.9 Expertise Levels in Health Care Tasks

Since the care providers have to take care of the patients' healthcare needs, their knowledge levels to perform the skilled care tasks were analysed. The tasks considered include administering insulin, giving injections, urinary catheter care and maintenance, tracheotomy suctioning, wound dressing, bed sore care, administering medications, monitoring blood pressure and blood sugar levels, etc. Only about 5% are nursing educated and thus carry out all of these tasks. 10% have obtained some training to carry out nursing activities. While 12.67% have learnt these tasks from doctors and nurses during their stay in hospitals as bystanders for their clients, another 16.67% reported performing the tasks as they have gained experiential knowledge by being in the field for several years. This category also includes a few who learnt some healthcare tasks from their clients

and families. Some recalled instances of the patients' relatives teaching them how to administer insulin or properly do nasogastric tube feeding. Almost one-fifth reported they could do not all but some of the tasks. These people find procedures like administering insulin and giving intravenous injections complicated since they require extra care and attention.

It is already stated that 38% deal only with the personal care tasks of the patients and thus, do not have any experience concerning healthcare procedures. Out of these people, almost half are interested to learn the tasks. In contrast, one-fifth expressed disinterest in learning seemingly complex tasks such as administering insulin or understanding catheter care and maintenance. A small category (3.33%) voiced that they are scared to execute healthcare tasks for the worry of getting blamed if something goes wrong. Such HNs help the patients only with ADL, cook food for them, and assist in other household chores if they are asked to. Among the 19 postnatal caregivers, 15 felt that they do not have to learn any healthcare procedures related to other illnesses since there is no requirement. Out of the four women who know to carry out healthcare tasks, one has received training of some kind, two have partial knowledge, and the other has learnt through experience in the field.

Some HNs stated that they sometimes care for the patients without knowing their illnesses. In most such cases, the family members keep the medicines in boxes and label them according to the dosage and timings- such as morning, afternoon, night, or before and after food. The HNs administer them to the patients on time. Since they are not educated in the nursing/ medicine field, they do not know what illness the medicines are given.

It was enquired if the HNs' knowledge of healthcare tasks became helpful in taking care of their ill family members. A substantial proportion of the respondents (44%) were happy that the knowledge and experience they gained as an in-home care provider came in handy when their

family members fell sick. However, a more significant number of people (56%) did not find it helpful. They were either unable to perform the required tasks due to their unavailability, or their family members did not develop any severe illnesses to carry out these tasks. It is worth mentioning that some informants interested in learning the healthcare tasks wished they received better training from the agencies to accomplish their duties much more efficiently. This throws light on the lack of training concerning the performance of medically oriented care needs.

2.10 Training from Nursing Agencies

It was analysed if all the HNs who seek employment through nursing agencies received any training that helps them carry out their duties better. The majority did not receive any kind of training from their agencies. A total of 19 HNs (including three people who went abroad) stated that they were provided with some training with respect to performing healthcare tasks.

The type of training provided to these HNs by their respective agencies was also explored. Sixteen care providers mentioned that they were given at least three weeks of training. The maximum period that was reported was three months. The HNs associated with the Indian Red Cross Society have received elaborate lectures and practical sessions of the nursing procedures from experienced doctors and nurses working at government hospitals. Those informants who belonged to the Red Cross Society stated that they used to maintain the nursing attire and had white uniforms earlier as they were trained to work as professional nurses. However, these days they have only their white coats and badges of their organization.

Table 2.8: Training given to the HNs

Sl. No	Characteristic	Numbers and Percentages (in parentheses)
1.	Training Given by the Nursing Agency	
	Yes	16 (10.67)
	No	118 (78.67)
	N.A., not via an agency	13 (8.67)
	Yes, since worked abroad	3 (2)
2.	Type of Training	
	One week class on health care tasks	1 (0.67)
	Many weeks/ months of training	16 (10.67)
	Just occupational socialization related	2 (1.33)
	N.A., not trained	131 (87.33)

2.11 Alternate Job Options

Since the HNs work for a private, unorganized sector, there is no guarantee that they will manage to get employed throughout the year. It was explored if they had any other income source if they did not have work. Only about one-fifth would perform some other work when they do not find any caregiving contract. More than three-fourths did not have to / did not want to rely on other occupations. Many of the respondents opine that they got employed throughout the year and did not have to worry about searching for another job.

2.12 Home Nurses Who Migrated

There are a few caregivers who have migrated internally and internationally. About one-tenth of the sample worked in other states of the country. The employers of these HNs are said to

have approached the nursing agencies. Thus, the HNs were sent to cities like Bangalore, Delhi, Mumbai and Hyderabad to work for Malayali families settled there.

Apart from this, eight HNs have worked abroad. Out of them, three were hired to take care of the ailing elderly, whereas the rest worked as nannies. Those who worked in other countries mentioned the differences they experienced while working in both countries. The main differences in a foreign country are better working conditions and salary and better respect for caregivers' jobs. However, a couple of HNs reported difficulties working abroad and had to return to their homeland soon.

Here is the case study of Beena, who has migrated to Israel.

Case - 03

Beena, a woman in her late forties, has been working as a live-in caregiver in Israel. She has eight years of work experience. Before moving to Israel, she used to work as a tuition teacher for school children. Before leaving the country, she underwent some training on basic healthcare tasks and geriatric care in Mumbai. She is a widow who has some financial difficulties owing to the debts her deceased husband could not repay.

So far, she has worked with three families to take care of the elderly who suffered from mental health issues and lifestyle diseases. The first two patients have passed away, and she was with each of them for about three years. She says that only the patient and the care provider stayed in all the homes. The family members would come to meet the patient weekly.

Beena has learnt Hebrew, the native language, which helped her get along with the patients and their families. She still stays in touch with the previous clients' kin, and it was through one of those families that she got the present contract. She says that more than half of the elderly patients'

care expenses are funded by the government, and the patients' families pay the remaining amount. She adds that caregivers also get some monetary benefits after the death of the cared-for person.

She feels that Israel is a country that is safe for women. She states, "the main difference between the situations in India and this country is that we are not treated as servants, but as professionals who provide healthcare. There is more value to the work we do. Our visa is not a maid visa but a caregiver visa. One advantage is that there is no work overload as such, and there is enough respite. We need not work all the day like machines, unlike many home nurses in Kerala".

She feels that stubborn and agitated patients are there everywhere. However, if the care provider learns to behave well and adjust, everything will be fine. At the last client's home, she did not have much workload. She was treated like a guest during the clients' family gatherings. Though this is her case, she cautions that there are families that mistreat the migrant caregivers as she has personally known people who have been through challenging situations. She is happy about the work conditions and all the facilities that have been made available to her by the clients' families hitherto. After a couple of years, Beena plans to return to her homeland. She revealed her wish to work in an elderly care home in Kerala and do the services for free.

2.13 Challenges Posed by Social Expectations

2.13.1 Making the Occupational Identity Public

While more than half of the informants stated that all their relatives and friends are aware of their occupational identities, 44% have revealed their involvement in caregiving only to their close relatives/ immediate family. It was surprising to note that about 5% of the respondents did

not even let their family members know that they are working as in-home care providers. Out of these seven people, four are men.

In most cases where relatives and friends are aware of their jobs, the informants have received criticism, nasty comments, and negative responses for taking up the position of a caregiver who has to look after strangers. This has been severe in the cases of female home nurses. However, in very few cases, the relatives have encouraged the women to continue the job, mainly where these women are the sole wage earners for the families. For some caregivers, the death or ill health of their spouses was the reason to consider the work of an in-home care provider. Otherwise, they would not have taken pains to either stay in a stranger's home or involve in a stranger's personal care tasks.

Some of the respondents had kept the matter hidden from their relatives. However, when their relatives came to know about the job, none supported them to continue with the job or appreciated them for doing an excellent service by looking after the ailing. Some even commented that the HNs would bring a bad name to their families if they continue to stay in strangers' homes or take care of male patients. A few people recollected instances when they were laughed at by their relatives who told them that they stink the urine and excrement of patients.

Some caregivers have informed others that they are either continuing with their previous jobs or doing different work. It was noticed that most HNs do not prefer to work near their place of residence. Though this is the case, most female HNs like to work somewhere within the district. However, a few women work in an adjacent district since they have many distant relatives spread across different parts of their own district. For instance, a few respondents from the Idukki district work at Ernakulam and some from Trivandrum work in the adjacent district of Kollam.

2.13.2 Working for Relatives or Acquaintances

As informed by some caregivers, a few of their relatives and friends have encouraged them to work as live-in care providers. Given that case, it was explored if the HNs had ever worked or liked to work for a known person. Less than one-tenth of the sample responded positively. Out of the remaining people, 38.67% did not find any such situation where they had to work for their acquaintances. They also added that they do not want to be employed by their relatives or friends even if such situations arise. The other 53.33% denied whenever they were about to be assigned such contracts by the agency. Those who have not revealed their identities as care providers see that they avoid choosing clients who are their distant relatives, mutual friends, or anyone linked to their connections.

2.14 The Roles Assigned and Roles Performed

2.14.1 Tasks Carried Out by the HNs

The care providers' tasks were categorized as personal care tasks and healthcare tasks. The former includes Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL). Tasks such as assistance with bathing, toileting, dressing and eating come under ADL, whereas activities like preparing meals, housekeeping, doing laundry, shopping or accompanying the patient to the hospital are considered IADL. The caregivers must assist in all the ADLs and some of the IADL as per their convenience/client requirements. A little less than two-thirds carry out healthcare and personal care tasks, performing roles similar to the home health aides mentioned in the introductory chapter. The remaining did not attend to the patients' healthcare needs, such as administering insulin and providing urinary catheter care. These people correspond to the West's

home care aides or personal support workers. However, some of them expressed interest in learning healthcare tasks to better look after the patients.

2.14.2 Involvement in Domestic Chores

More than three-fourths of the sample (79.33%) provide or have provided housekeeping support to their clients. Their chores include helping to cook and do the dishes, cleaning the house, doing laundry, running errands, or sometimes cleaning the house's surroundings. Thirty one respondents stated that they adhere to the norm of carrying out activities related to the patient's care alone. This section of caregivers includes 11 men and 20 women.

It was noted that most of the HNs help in the household tasks even if their clients do not formally ask them. Several female caregivers mentioned that they do not like to sit idle and help in the kitchen or do cleaning tasks during their free time. These people think that since they are women, it is not fair on their part to sit and enjoy the food served to them. Instead, they too should contribute to cooking the food, at least by chopping vegetables. Some express their concern in making the clients' female relatives work alone when they can offer them some help. However, some HNs also mentioned that sometimes clients take advantage of them if they find that the caregiver is willing to offer housekeeping support. One of the respondents cited an instance of a client demanding her to take care of cattle. She denied doing the task as it was not mentioned anywhere in the contract.

On the whole, as the interviews reveal, there is a great amount of role ambiguity for the HNs, even though their employment is based on explicit contracts. This acceptance of role ambiguity is thus on mutual informal agreements and is felt to be for mutual advantage to them and their clients. Their role performances seem to depend on their acquired skills, relationships with their clients, and the extent of role ambiguity experienced by the HNs.

2.15 Work Environments

The work environment for the HNs was examined chiefly in terms of the family backgrounds of the clients they served, the nature of illness of the clients, and the tasks assigned to the HNs. As many caregivers attended to patients with varied illnesses and different family backgrounds from the start of their careers, the data explicitly obtained on the work environment for the current clients and/ or the last client was analyzed first. Subsequently, some general information on the clients served earlier has also been dealt with.

2.15.1 Age of the Client

The majority of the care providers looked after patients aged above 60 years. The greatest number (38%) of HNs had clients aged between 71 and 80. More than one-tenth of the informants tended to clients aged above 90 years. A quarter of the HNs was involved in the care of patients aged below 60 whereas, only 6% had clients aged less than 30 years. The postnatal care specialists reported the ages of the mothers and not the babies. The ages of most of their clients ranged between 25 and 35.

2.15.2 Family Type of the Client

Very few HNs (16%) served clients that belonged to joint families. This could be because the number of joint families is less in the study area (compared to the Northern part of Kerala). Secondly, members in joint families are more likely to be cared for by informal caregivers. Several informants reported working at homes of elderly patients who lived separately with their spouses while their children stayed in nearby homes. Those elderly patients who stayed in their adult children's homes are counted under nuclear families that consist of three generations.

Many home nurses indicated working for the parents of Non-Resident Indians (NRI). In some such cases, cameras were installed in the houses as a kind of surveillance system so that the children could keep track of their parents' health conditions and monitor the caregivers' activities.

It could be known that more than half of the respondents have worked in homes where only the patient or the elderly couple stayed alone. The majority that worked in these environments were not overburdened as they had less work to do. However, such a work setting was unfavourable for some others due to safety/ security issues. They believed that staying with large sized families was a safer option.

2.15.3 Religious Backgrounds of the Families

Most of the HNs (56.67%) were hired by Hindu clients in their last or ongoing contracts. More than one-third worked with Christian families and 6% with Muslims. One of the respondents worked with a Jewish family as she was working in Israel. Most informants were satisfied with their clients and did not worry about their religious background. Some HNs, however, made negative comments on their clients based on the stereotypes and negative prejudices about these communities/ castes that are prevalent in the state. For instance, some expressed reservations about working with Muslim families stating they are less hygienic and their cooking style is difficult to adjust with, though they treat them well in terms of the provision of food. Likewise, some others voiced that they worked with Christian and Hindu (Nair) clients reluctantly as they had not given them enough food. Similar issues of cultural compatibility have been explained in the chapter on clients' perspectives. Instances of caste discrimination faced by the caregivers are discussed later in detail under relevant sections.

The HNs shared details about the religious affiliations of the past five clients they served. The ones who had not worked for those many clients provided the details of clients with whom they had worked so far. While around 45% worked for both Hindu and Christian clients, one-third were employed by Hindus, Christians, and Muslims. About one-tenth had only Hindu clients, and a meagre 2.67% worked solely for Christian families. As stated above, one of the respondents who works in Israel has served only Jewish families. Only two respondents worked only for Muslim clients ever since their career as HNs. These two people were Hindus. Out of the 9 Muslim caregivers, it was found that all of them worked for clients belonging to all the three dominant religious groups in Kerala. They did not mention that they preferred Muslim clients to clients of other communities.

2.15.4 Employment Statuses of Clients' Female Relatives

It is often the women who act as primary caregivers for their significant other who is ill. However, several studies have observed an increase in men taking up caregivers' roles. It is found that the need to have a formal caregiver is felt only when the patients' female kin cannot provide care for various reasons. One of the main reasons cited is women's paid employment. In a few cases, the patients did not have any female relatives present because they did not exist or did not co-reside. The HNs were enquired about the employment statuses of their clients' female relatives. It was found that close to half of the present employers belonged to the category 'families with employed female members'. One-third of the respondents worked for patients who did not have any female relatives to support, like in the case of patients who are the only women members of nuclear families.

To identify if women's employment relates to hiring a formal caregiver, the HNs were queried about the occupational details of female family members of their previous clients. It was

found that about 15% have worked solely in homes where female family members were employed. A meagre 2.67% noted that all the women in the homes of their past few clients were unemployed. All the remaining worked in some homes that had employed women and others that had women who were homemakers. As assumed, several clients require a formal caregiver's services due to female family members' employment. However, many clients with unemployed female kin also rely on home nursing services for various reasons. This is discussed later in detail in the chapter concerning the theme.

2.15.5 The Financial Status of the Client's Family

It is already understood that the clients have to pay the caregivers a monthly salary anywhere between 10,000 and 25,000. However, the caregivers were inquired about the economic statuses of their clients. Close to two-thirds (63.33%) indicated working with clients from middle-class backgrounds. While more than one-third worked with affluent clients, only two had been with patients from economically poor households. In such cases, the patient's medical expenses and the HNs' salaries were taken care of by their church groups that contribute to the destitute's charity and medical treatment.

2.15.6 Illness of the Client

In their last assignment, almost one-third (32.67%) of the HNs cared for elderly patients who suffered from age-related weaknesses. About 15% served patients who required post-surgical care. Nearly an equal number looked after patients who suffered a stroke. While 12.67% attended women who required postnatal care, about 16% tended to patients who suffered from lifestyle diseases like diabetes, hypertension, or other diseases like cancer, pulmonary disease, dementia,

and mental illness. The remaining were employed to manage patients who did not have any severe conditions but just required care and assistance with ADL and IADL.

2.15.7 Illnesses of Past Few Clients

To explore the most common illnesses for which clients use home nursing services, care providers had to enumerate their past few clients' ailments. The diseases were grouped based on the different combinations that the respondents suggested. Half the respondents looked after patients with lifestyle diseases, heart disease, cancer, stroke, or age-related illnesses. The past few clients of around one-fourth required help with post-surgery care or were suffering from conditions like lifestyle diseases, heart disease, cancer, and stroke. 7.33% served elderly patients who had illnesses associated with old age. Nineteen informants dealt with cases of postnatal care in their past few assignments. Among them, 11 exclusively focus on post-pregnancy care, whereas the others also take up contracts with patients who suffer from other illnesses.

2.15.8 Term of Employment

There were only a few cases (4.66%) where the HNs stayed with their last client for more than a year. The duration of the contract with the last client was between six months to a year for about one-tenth of the informants. Thus, it is apparent that most of the HNs work for a client only for about a couple of months. This is either because the nursing agency does not allot an HN to a particular client for more than a specified time or due to the client terminating the services. Close to half of the sample stated that they were with their last client for a month, and less than one-third for not more than three months. It was also found that about 7% remained in their last contract for less than a month. This must have happened for various reasons, but one of the main reasons is

their compatibility issues with their employers. Those HNs who find it difficult to get along with the patient or family try to adjust for a few days, and if it does not work out, they leave the contract.

The duration of the HNs' contracts with the past few clients (up to 5 clients) was analysed. Nearly two-thirds stayed with all their clients for a few months. This category included all the HNs who spent more than a month but less than a year at all the places they stayed. A little over 30% continued with some of their past clients for a few months and with some for more than a year. Some of the HNs who stayed longer with some clients mentioned that if the nursing agency rules allow them, they can continue with a particular client as long as they require the service. 5.33% stayed with each of their past clients precisely for a month.

Table 2.9: Details of current/ last client

	Characteristic	Numbers and Percentages (in parentheses)
1.	Religious Affiliation	
	Hindu	85 (56.67)
	Christian	55 (36.67)
	Muslim	9 (6)
	Jewish	1 (0.67)
2.	The Financial Status of the Family	
	Well off	53 (35.33)
	Middle class	95 (63.33)
	Economically backward	2 (1.33)
3.	Family Type	
	Joint	24 (16)

	Nuclear (including elderly couple alone/ patient alone houses)	126 (84)
4.	Employment Status of Female Kin	
	Employed	69 (46)
	Unemployed	31 (20.67)
	The client does not have female relatives	50 (33.33)
5.	Client's Illness	
	Diseases like B.P, cholesterol, diabetes	14 (9.33)
	Diseases like heart disease or respiratory diseases.	1 (0.67)
	Cancer	6 (4)
	Stroke/ paralysis	21 (14)
	Kidney failure	2 (1.33)
	Alzheimer's/ dementia	5 (3.33)
	Mental illnesses	1 (0.67)
	Post-surgery care	22 (14.67)
	Age-related weakness	49 (32.67)
	Postnatal care	19 (12.67)
	No serious illness. Only care and assistance needed	10 (6.67)
6.	Client's Age (in years)	
	Less than 30	9 (6)
	31 to 40	17 (11.33)
	41 to 50	2 (1.33)
	51 to 60	8 (5.33)
	61 to 70	23 (15.33)
	71 to 80	57 (38)
	81 to 90	17 (11.33)
	91 or above	17 (11.33)

7.	Duration of Employment	
	Less than a month	11 (7.33)
	One month	71 (47.33)
	1-3 months	44 (29.33)
	6 months	8 (5.33)
	Around a year	9 (6)
	1-2 years	2 (1.33)
	More than 2 years	5 (3.33)

Table 2.10: Details of past few clients

	Characteristic	Numbers and Percentages (in parentheses)
1.	Religious Affiliations	
	All Hindu	17 (11.33)
	All Christian	4 (2.67)
	All Muslim	2 (1.33)
	Hindu and Christian	65 (43.33)
	Hindu and Muslim	5 (3.33)
	Christian and Muslim	5 (3.33)
	All three religions	51 (34)
	All Jews	1 (0.67)
2.	Illnesses of Past Few Clients	
	Cancer	1 (0.67)
	No severe illness. Care and assistance needed	2 (1.33)

	Alzheimer's/ dementia	1 (0.67)
	Post-surgery care	1 (0.67)
	Age-related weakness	11 (7.33)
	Lifestyle diseases, heart disease, cancer, stroke, geriatric care	75 (50)
	Post-surgery care, Lifestyle diseases, heart disease, cancer, stroke	40 (26.67)
	Postnatal care	11 (7.33)
	Postnatal care +geriatric care	4 (2.67)
	Postnatal care + Lifestyle diseases, heart disease, cancer, stroke, geriatric care	4 (2.67)
3.	Employment Statuses of Female Relatives	
	All employed	23 (15.33)
	All unemployed	4 (2.67)
	Some employed, some not	123 (82)
4.	Duration of Employment	
	All in less than a month	0 (0)
	All in a month	8 (5.33)
	All in a few months	93 (62)
	All more than a year	1 (0.67)
	Some in months, some in years	47 (31.33)
	Some in days, some in months and years	1 (0.67)

2.16 Tasks Performed by the Caregivers

Activities carried out by the HNs are broadly categorized into ‘health care related’ and ‘non-healthcare related’. Concerning the former, the task of ‘hospital bystanders’ has a special significance for its implications on ‘status perceptions’ and the improvement of their home nursing skills. Given this, the aspects pertaining to hospital bystanders’ roles are discussed in detail below.

Nearly two-thirds of the informants have been bystanders when their clients were hospitalized. This number has included HNs who attended to clients that suffered from various chronic or terminal illnesses and others that required shorter stay durations, such as post-surgery or post-delivery hospitalization. It was examined if the HNs were informed by the clients/ their relatives that they would have to stay with the patient whenever hospitalization was required. The majority (about 83% of the bystanders) were informed beforehand. The remaining neither expected that they would have to be bystanders nor considered it part of their duty. Some of them believed that in-home care providers need not be involved in matters outside the clients’ homes.

The care providers were enquired about the illnesses of such patients for whom they were the only hospital bystanders. It was to understand the nature of illnesses and find any particular cases that the clients’ relatives consider not severe enough to have their presence at the hospitals. Nearly half of the cases were of elderly patients who had age-related illnesses. There were about 19 cases of post-surgery care, and the rest suffered from conditions like cancer, cardiopulmonary diseases, kidney failure, stroke, and mental illness. All of them were elderly or middle-aged patients. Thus, it is not just the severity of the illness that decides if relatives of the patient stay at the hospital, but factors like the patient’s age also affect their decision.

2.16.1 Reasons to Become Hospital Bystanders

Out of the informants who have been bystanders, about 83% served as the patients' sole bystanders. In other words, they were the only ones who stayed with the patient throughout the period of hospitalization. The patients' relatives accompanied the HNs in case of the remaining.

These informants' reasons for why they had to be the only bystander for the patient were analysed. It was assumed that the majority would reason that more than one bystander is not allowed in the hospitals. However, only five people mentioned this as the reason. One-third stated that either the patients were nearing death or their illnesses were not serious that their relatives did not stay in the hospital. About a quarter informed that they were paid to do the task; thus, the patients' relatives did not bother to stay. The remaining reported that they had to be the sole bystanders since the clients' relatives were either unavailable or uninterested in staying at the hospital.

2.16.2 The Role of Hospital Bystanders: Challenges and Opportunities

It was examined if the caregivers faced any difficulties during their hospital stay. Close to 45% stated that they did not have any difficulties as such. Almost an equal number pointed out that they were sleep-deprived during those days of hospital stay. The conditions of several patients required their bystanders to stay awake during the night. But, these caregivers could not sleep during the daytime. Two respondents found difficulty with food as they could not adjust to the food available at hospital canteens. The remaining six opined that they were made to do so many tasks during the days of their clients' hospitalization. They also state that if the hospital staff (mainly nurses) know that it is not a relative but a home nurse who is the bystander, they delegate most of the patient's personal care tasks on the HN.

Several informants mentioned that they prefer being a hospital bystander to an in-home caregiver. Such people have a few reasons to justify this. One respondent says, “Being at a hospital will not fetch you the bad name that you are staying in a stranger’s home, as it is a safer option than staying in a house that has unknown men”. Another participant feels that being a bystander is beneficial in terms of the money one earns. She explains, “Sometimes the relatives of the patient who come for a visit will also pay us some money. As a bystander, you will often be paid Rs 700 daily (Rs 500 for the duty and Rs 200 for food expenses). This is gainful since we can reduce our food expenses and save some money”.

Some HNs believe that the stay at the hospital is beneficial since nurses and doctors would be there for help always, and they need not worry much about the patient. They also consider this an opportunity to learn some healthcare tasks and procedures from the doctors and nurses.

2.16.3 Learning Healthcare Tasks from Hospital Staff

Some of the caregivers already stated that they learnt several healthcare tasks during their roles as bystanders for their hospitalized clients. Half of the bystanders reported that their experiences were beneficial since the nurses and doctors were cooperative enough to teach them some procedures that help them to take care of their clients. The remaining could not learn any medically oriented practices.

Out of the 48 respondents who had a learning experience, 21 were taught to provide urinary catheter care and properly tube feed the bedridden patients. The staff nurses trained 11 others on dealing with bedsores and changing bedsheets without moving the patient out of bed. Nine HNs

were happy to learn to administer insulin and monitor blood pressure. The remaining seven learned some basics about carrying out personal care tasks and assisting the patients in ADL.

Table 2.11: Healthcare tasks learnt during the hospital stay

Task learnt	Numbers and Percentage (in parentheses)
Monitoring BP, Administering insulin	9 (6)
Catheter care, tube feed	21 (14)
Bed making, Bedsore care	11 (7.33)
Basics of caregiving	7 (4.67)
N.A. since could not learn/did not do the job	102 (68)

2.17 Non-Health Care Tasks of HNs

The HNs were queried about the tasks they performed in the past few clients' homes. Only 12% stated that they were exclusively hired for the patient's care in all the homes. One-tenth had to do patient care and household tasks in all the recently worked places. More than half of the sample (52.67%) were involved in household chores in addition to patient care in most of the homes they worked. However, a quarter reported that they had to carry out only patient care in most homes. As it could be known from the HNs, they are formally hired by most employers to render care to the patients and not do other household chores. Nevertheless, many HNs offer housekeeping support voluntarily.

2.18 Home Nurses' Role in Postnatal Care

As stated in the previous sections, 19 women (12.67% of the sample) provide post-pregnancy/ postnatal care. Some of these people involve in both postnatal care and the care of patients suffering from other medical conditions, while the others are exclusively into the speciality. They deliver care for new mothers and newborn babies. Depending on the clients' requirements, they are mostly hired for a month or forty days. Muslim clients usually employ the postnatal caregiver for forty days.

It was analysed if these women had served as midwives or traditional birth attendants (TBAs). Only two of them were midwives earlier, and both of them are aged above 65. All but four postnatal care specialists were aged above 50. It is usually a bit elderly and experienced women who are preferred to young women. It could be known that clients prefer women who have either had experience as birth attendants or have taken care of their own children and grandchildren. Some women are assumed to have a knack for dealing with newborn babies and giving proper care to feeding mothers.

It was explored if the mothers or grandmothers of any of these informants were birth attendants. Out of the 19, the previous generations of 15 were involved in the same activity. Also, all the postnatal specialists except four were associated with nursing agencies and thus worked in places far from their homes. The other four mainly worked for clients who were acquaintances or people who belonged to the same district.

Similarly, barring four women, none helped their clients with their household chores since they did not want to do any work unrelated to the newborn and its mother. Usually, the tasks of the postnatal care providers include preparing Ayurvedic/ herbal medicines and other special food

items that new mothers are suggested to consume, giving a bath to the baby, giving herbal oil massage and bath for the mom, and doing the laundry of the baby and mom.

2.19 Perceptions of the Work

The postnatal caregivers' perception of their work was explored to determine if there is a demand for traditional postnatal care providers as most clients rely on allopathic medicine and modern healthcare systems. All the respondents believed that their services are in great demand and people trust traditional postnatal care providers like them. The case of a postnatal caregiver named *Ponnamma* was mentioned earlier in this chapter. Here are a few observations from her life history.

Ponnamma says that she used to care for elderly patients and others suffering from chronic ailments until seven years ago. It was then that she became a postnatal care specialist. Her mother was a midwife, so she knew the procedures related to post-pregnancy care. She finds this work less difficult comparatively as she does not have to perform much physical labour. Neither does she have to involve in household chores at the clients' homes. Besides this, she gets paid better at present, and she says that she earns more than Rs. 20,000 a month. She is content that all her clients have been very good to her, and they have treated her with love and respect. She does not have any kind of homesickness since she does not get treated well by her family. She is pleased with several of her clients' approach to consider her a parent figure while her own children made her destitute. *Ponnamma* is grateful to the job for sustaining her life and introducing her to many patients and families. She adds that most of them refer to her as *Amma*. She believes that postnatal caregivers like her (especially older women) are respected by the clients.

A few women who provided neonatal care continued working as nannies or babysitters for some clients. In most such cases, both parents of the children were working, thus requiring a full-time child-carer. For instance, an informant named *Mary* had taken care of a child for more than a year. The child was so fond of her since she spent most of the time with him while his mother worked. The child calls her "*Ammamma*", which means grandmother. Now that the couple and the kid are planning to shift to Australia, they insist Mary accompany them.

It was found that none of the HNs except one experienced any kind of stigma due to being a postnatal caregiver. However, only seven out of the 19 mentioned that they have worked or like to work with relatives, friends, and acquaintances. When enquired, they stated that they do not want to negotiate the salary with familiar people. One of the respondents says, "At times it so happens that when we work for our acquaintances, it will be awkward to discuss salary with them. But with strangers, it is okay to negotiate and get a reasonable amount for the work we do".

These caregivers are happy that their work fetches them a decent salary that helps keep their families going. Also, all of them mentioned this aspect as the main reason to work as postnatal care providers. Some of these HNs earn anywhere between 18000 to 25000 rupees, which is at least 5000 rupees more than what HNs who take care of other patients make. It was informed by most of these postnatal care specialists that they are given extra cash, some gift/ new pair of clothes or other goodies at the end of the contract. Sometimes they get money from the relatives who visit the newborn and mom.

2.20 Academic Nursing Qualified Caregivers

Though there are only a few nursing qualified informants, it could be worthwhile to understand how their work experiences are different from the others. Their reasons for entry into this profession have also been analysed. As reported earlier, seven respondents are academically nursing qualified. They all left their clinic-based jobs to serve as in-home care providers since they were not happy with their salaries, work conditions like night shifts, personal concerns such as health issues, and how the hospitals were organized. The following select case studies illustrate these issues faced by qualified nurses.

Case - 04

Mani is a 45-year old caregiver who works for the Indian Red Cross Society's branch at Pathanamthitta district. It has been eight years since she started working here. She has a bachelor's degree in English literature. Mani completed a one-year course in Auxiliary Nursing and Midwifery (ANM) besides receiving some training from the Red Cross. She knows to execute procedures such as nasal feeding, urinary catheter insertion, administering insulin, Intravenous and Tetanus injections and tracheotomy suctioning. She worked as a nursing assistant at a hospital for a short period. She left the job due to some health issues she had then. Though the work of home-based caregivers is easier in several respects, she feels that hospital nurses enjoy better societal status. Despite this, she is glad that she is associated with an institution like the Red Cross Society, which is recognised worldwide. She says that the caregivers of the Society are treated with more respect, unlike those from other private nursing agencies who are at times considered as home helps. She also points out that Red Cross's staff used to have their white uniforms, badges, and overcoats earlier. Now the staff does not have this professional attire. In her opinion, the uniform attire used to be their distinct identity as it gave the nurses a more dignified and modest appearance.

Mani recalls some disapproval from her family when she switched to home-based care. Nonetheless, her husband was later fine with her continuing in the job. Since her husband works abroad, she does not like to work in other districts. She says that she has to keep an eye on her daughter, a school student. Though she has a good opinion on all the clients and family with whom she has worked so far, she follows a practice of ending the relationship with a client as soon as the contract with them ceases. She does not remain in touch with any of her previous employers unless for some genuine reason.

Case - 05

Suma, who worked for eight years as a nurse in a hospital, took up home-based care about two years ago. She is in her late forties and suffers from diabetes. Due to her ill health and the difficulty to work night shifts, she had to leave the job. Suma does not like to stay idle and joined home nursing despite her family's disapproval. Her distant relatives and friends think that she still works at the hospital. Since she has been working part-time, they believe she comes home after hospital duty. She does not want to work full-time as she has two girl children who need her care and attention.

She understands that hospital nursing is more respectable than home-based caregiving and thinks the latter is often considered unqualified and uneducated. In her opinion, nursing is a job anyone can perform. All it requires is patience and the interest to look after the sick. She says that the caregiving qualities of a person do not have any connection with their gender.

Case - 06

Jaya, who used to work as a nurse in a clinic, has a story similar to Suma's. It has been five years since she joined the home-based care sector. Only her immediate family members are aware of her job identity. All other relatives still believe that she continues to work at the hospital. She is concerned about the criticism or disapproval that she would have to go through once revealed to her kin. She is afraid they would speak low of her due to some people's perception that home nurses are promiscuous women.

She currently takes care of an 82-year-old man who is paralysed. She has been with this patient ever since she began home nursing, and at present earns Rs. 16,000 monthly. Though she is satisfied with the work conditions and salary, she feels that the job lacks honour. She likes to be a staff nurse at a hospital since that role is better recognised and professional.

These cases reveal that qualified nurses find in-home caregiving easier than the tight schedule and tiring night shifts at hospitals. The informants experience a better work-life balance now though most of them stay away from their families. They also seem content in the care imparted to the patients as it is personalized care delivered at their comfort. However, they realise that clinic-based nurses have a better societal status and home nurses are suspected due to the work location. It is revealed that the nursing attire reflects professionalism, and the nurses wish to wear their uniforms in home care settings. Their families do not favour their shift to home care despite the job fetching an improved income. Some have not disclosed their relatives about the job shift

due to the lower status and stigma attached to domiciliary care work. They specify that home nurses are often considered unqualified and uneducated. If not for the better salary and lesser workload, most of them would have continued hospital-based nursing since it is certified and accredited.

2.20.1 Job Satisfaction

All qualified nurses except one found that the duty of a home-based caregiver is easier than a hospital nurse's. The only informant for whom domiciliary care is more complex than hospital nursing reasoned that some clients' families wanted her to perform household tasks besides caregiving.

The informants who worked previously in hospitals revealed that the present job paid them better. While three people expressed that they were very satisfied, the rest were moderately satisfied. They seemed to be happy not just with the salary but with the work they were carrying out. When they are better able to concentrate on patients by spending more time with them, it boosts their morale.

Here are the cases of two care providers who work together but have different stories to share.

Case - 07 and Case - 08

Indu and Sajna, two informants in their early twenties, are nursing qualified. Now they are working in an elderly residential care home in the Thiruvananthapuram district. The institution has more than twenty residents. This elderly home is run by a person who owns a few home nursing agencies across the state.

It has been six months since Indu joined the place, and she has about four years of experience working in a hospital. She prefers staying here to staying at individual clients' homes. She found it hard to adjust to the hospital work conditions and switched to this setup. She is comfortable in this role as a caregiver for the elderly compared to the previous job. Nevertheless, she has not informed any relatives/ friends that she is working here. Everyone thinks that she is still a hospital nurse. Indu does not like being referred to as a 'home nurse'. She voices, "The term kind of belittles my qualification. I'm an academic nursing qualified person, and I do not wish to be compared to home nurses who barely know the basics of nursing". She thinks that she might not continue working here for long. She conveyed her wish to migrate to some foreign country if she gets an opportunity to work as a staff nurse.

On the other hand, Sajna does not have any experience in clinic-based nursing. She completed her nursing course and directly joined this elderly care home. She liked to be a live-in caregiver so that she could provide individualized care to the patients. All her relatives know where she works. She enjoys the work, loves to be with the elderly, and feels delighted to offer them good service. She is satisfied with the label 'home nurse' as she believes that a title or name does not affect the duty that she performs. She adds that many people in the home care field have learnt the nursing activities with their experience in the industry. This does not make them less qualified.

Both young women (unlike other HNs) wear white uniforms similar to the scrubs nurses use. They like the working conditions at this care home as they feel that they are living with the elderly patients like a family. They are very fond of some patients who consider them like grandchildren. Indu and Sajna revealed that when they go home for two days leave (in a month),

they would be so worried about these elderly patients. They would soon want to come back and be with them. Indu recalled an incident where a patient kept aside some sweets she got from her visitors. She gave the sweets to Indu once she was back from home. Indu feels grateful for the love and concern the patients show. She says, “It is these little things that make me happy. If I were a hospital nurse, I do not think such moments would have happened”.

2.21 ‘Male’ Home Nurses

As was pointed out earlier, the published literature on nursing has dealt with the aspects of gender constructions and the differential expectations of men and women about the nursing profession. Given the opportunity to contribute to the existing knowledge in this area through this study, the researcher dealt with data on the male nurses separately. The findings based on the same are presented below.

2.21.1 Male Caregivers’ Perception of the Job

Home nursing in Kerala is a female-dominated sector, and the present study sample testifies the same. It was analysed whether the twenty male respondents perceived nursing as more appropriate to women and considered it a women’s forte. Not surprisingly, eight felt domiciliary care to suit women better. Out of the remaining, a few pointed out that ‘they are not ashamed’ to be in a female-dominated field since they are employed to take care of male patients alone. These men joined the job and desired to continue it for varied reasons.

Though it may not be statistically significant, the data revealed that some men were drawn into the sector due to the influence of their family members. At least two respondents explicitly agreed to be convinced by their spouses. Explained below is the case of one of them.

Case - 09

Binoy has eight years of experience as an in-home care provider. His wife introduced him to the field and motivated him to take up the job. They both believe that serving the sick and needy is a divine act. Currently, she works as a home nurse in Sharjah for a Malayali family settled there. In their absence, the couple's girl children are taken care of by their maternal grandparents. Binoy says that their daughters have become interested in pursuing their careers in nursing due to their influence.

He feels that one needs a lot of patience and willpower to remain in this job. He believes that one has to be a good listener while involved in geriatric care. Often, adult children do not have time to listen to what their elderly parents have to tell. Then, the care providers have to lend their ears to the stories of elderly patients. This will help develop bonding between the two and might also help improve the patient's health condition. Activities like reading newspapers aloud, telling stories, discussing politics, sharing news from the locality, and conveying messages from the patients' relatives that appear trivial also count. For him, emotional care is as critical as providing physical care.

In his opinion, though more men have been entering the home-based care sector lately, there is less demand for male caregivers. Due to this reason, men will have to contact multiple nursing agencies to procure a contract. Though better paying, Binoy left his previous job due to his interest in serving the sick. He claims that caregiving gives him satisfaction and peace of mind. Although he enjoys working as a caregiver and providing solace to the ailing, he has kept his caregiver identity undisclosed to his friends and relatives. Binoy says that the job could be challenging for men since dealing with elderly patients is hard, especially those who suffer from incontinence. He says that he did not receive any training from the nursing agency he is associated

with. Binoy learnt to perform almost all health care tasks (including basics of physiotherapy) from staff nurses while he stayed as a bystander for some hospitalised patients.

Case - 10

Ajeesh is a 32-year old transman who has over ten years of experience in domiciliary care. He is unmarried, and his family consists of his parents and siblings. His interest in caregiving led him to join the Indian Red Cross Society's Kottayam branch in 2007. From there, he was trained to do almost all the healthcare tasks. He can perform physiotherapy as well. Ajeesh is proud of his work, and all his relatives are aware of his caregiver identity. He opines that the job is a decent choice for people like him who do not fit into society's gender constructs. This work gives him enough freedom and fetches a decent salary. He gets paid Rs. 16,000 a month. He says that he continues in the job out of interest to look after the ailing.

2.21.2 Knowledge of Physiotherapy

Twelve of the twenty male care providers perform physiotherapy. Interestingly, out of the eight who do not have any physiotherapy knowledge, seven are aged above 50 years. They reported finding it challenging to learn the skills and not considering themselves physically strong enough to take up physiotherapy-related tasks.

Physiotherapy is usually not performed by the female HNs, and it is stated by both the male HNs as well as the agency owners as a speciality that men are into. However, four women mentioned that they could carry out the same. While two of them received some training, the others learnt the basics through observation. They consider it a prestige as this skill makes them distinct from other female HNs.

Out of the 12 who did physiotherapy, four either did a professional course or got some training from their nursing agencies. All the others observed physiotherapists perform it and learnt the basics.

2.21.3 The Stigma Around the Job

Out of the 20 male respondents, seven mentioned that they had experienced some humiliation as they involve in work that women typically do. Since their work is confined to homes, some men are dissatisfied. They state that men are not bound to be at home, do household chores, and perform caregiving activities in the realm of women. One of the men remarks, “Men do not get good marriage alliances if their occupational identity is revealed. They are prone to be considered less manly”. These people are ridiculed not just because men perform ‘women’s job’. Since the nature of the job is to provide hands-on care (often considered dirty work), some were put to shame. The following case highlights several issues that many men in the field may have experienced.

Case - 11

Joy is a 50-year old bachelor who has been working as a caregiver since 1997. He has learned all the nursing tasks from Thrissur Medical College, where he stayed for six months as a client’s bystander. He has worked for about five home nursing agencies so far. He keeps a count of the clients he has worked for and says that it is the 36th home that he is currently at. Before joining the care industry, he worked as a tailor.

Joy conveys that society has a terrible perception of male caregivers. People think that they are less masculine. Some clients have teased him, saying that he is a gay man. He says that

not just women but men are also prone to harassment and mockery. The case of unmarried men in this field is even worse. They are often mistaken as homosexual and are sometimes approached by men who have that sexual orientation. Joy said this from the experiences he and his friends have had. He has kept his identity as a live-in caregiver a secret from his siblings, other relatives or friends. They are made to believe that he works as a hotel cook.

Joy is proud of the services rendered by the home nursing community, and he derives much satisfaction from working in this sector. Ironically, he lacks the courage to inform anyone about his job. He fears that he would be humiliated if they get to know that he tends to sick, bedridden people. He comments, “They do not realise the value of the work we do. In their eyes, our work is all about dealing with human waste. I am afraid that I might be compared to a manual scavenger and ridiculed by some of my economically well-off relatives. But I am not going to leave this job that fetches me daily bread”.

2.21.4 Tasks Performed by Male HNs

The tasks performed by the male informants, apart from caregiving, was identified. More than three-fourths indicated that they had to run errands, go to medical stores, accompany the patients to hospitals/ clinics, and at times drive cars when the clients asked them to. However, most of them reported doing these tasks while employed in single-person households.

Some of the informants who were cooks earlier note that their experience has been helpful for them to cook for the patients who do not have co-residing relatives. The remaining did not perform any household chores or work that required them to step out of the clients’ homes.

Illustrated below is the case of one of the caregivers.

Case - 12

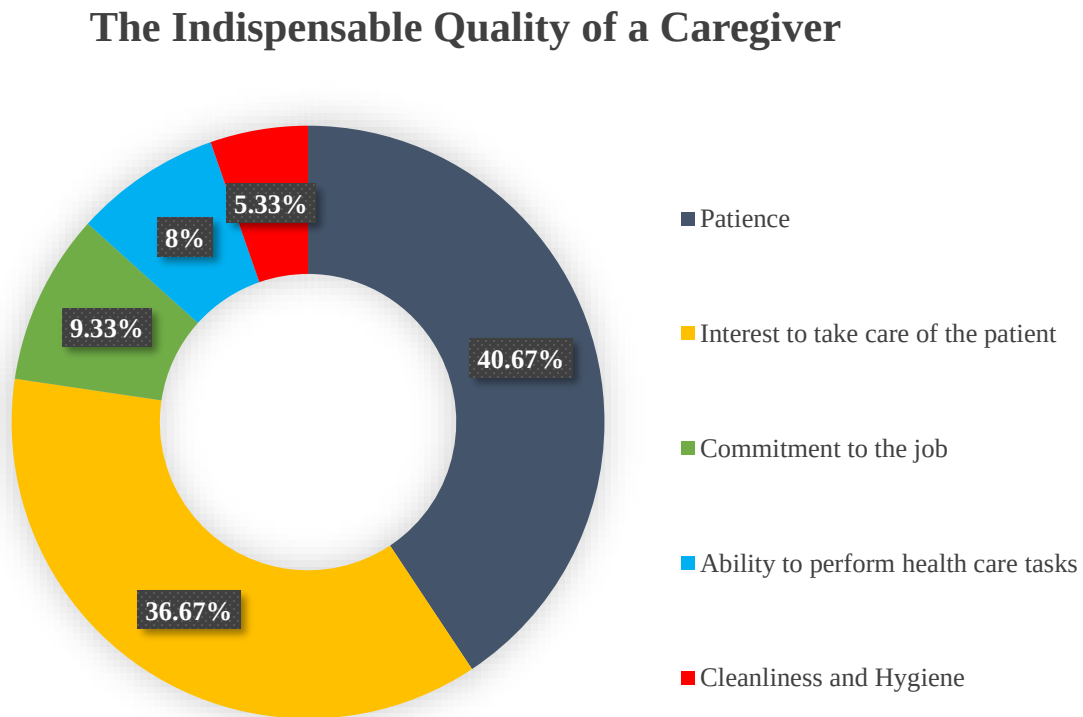
Sudhakaran Pillai, a TAMILIAN, settled in Kerala about thirty years ago. This 54-year-old man worked as a mason and later became a cook and now a caregiver. He has almost 15 years of experience as a care provider but does not work as one throughout the year. Whenever he does not find work, he takes up the role of a hotel cook. Pillai thinks that caregiving is not tricky unless your clients make it hard for you. Over the years, he has learned to carry out procedures such as administering insulin, tube feeding, monitoring blood pressure, wound dressing, and physiotherapy. He says that he has taken care of more than 50 patients so far. Whenever he stays in homes where the patients stay alone, he cooks for them besides assisting in others tasks of daily life.

2.22 Perceptions About Successful Role Play

2.22.1 The Indispensable Quality of a Caregiver

The care providers were inquired about the one quality they considered indispensable for their role. While the greatest number of informants recognised patience, it is the interest to look after the patient for more than one-third. Commitment to the job was rated the most valued quality by about one-tenth. Close to 5% felt cleanliness and hygiene are mandatory for a care provider. Interestingly, only 8% of the sample believed accomplishing healthcare tasks was the most needed quality for a home nurse. Among the 12 HNs who had this opinion, eight are nursing trained/academic nursing qualified. It has already been identified that nursing qualified informants consider the ability to carry out nursing procedures as a quality capable of raising the reputation of the domiciliary caregivers' job.

Figure 2.1: The indispensable quality of a caregiver



2.22.2 The Best Part of the Job

Many informants acknowledged the caregiver's role for instilling some humane qualities in them. They are confident that they have become more empathetic and tolerant. Upon exploring what gives them professional satisfaction, more than half of the caregivers (55.33%) opined that they like to care for elderly/ bedridden patients since it is a virtuous act to serve the ailing who are nearing death. Some revealed that they consider elderly patients like their parents/ grandparents. A few also mentioned that they could not look after their parents during their last days, and by

taking care of these patients, they are compensating for that. Several people stated that being a care provider for elderly patients is satisfying. The below case testifies this.

Case – 13

Kumari is a 47-year old lady with 18 years of experience working as a home nurse. Around 11 years, she worked in Kerala's Malappuram district, mainly as a postnatal care provider. She had been to Kuwait to work as a nanny but returned after three years. Right now, she works in the Thiruvananthapuram district at an elderly residential home that has only six residents. Though she does not have any nursing background, her strong desire to serve the ailing led her to pursue a career in caregiving. She is a widow who has two unmarried children. Everyone in her family knows about her work, and they support her.

When she went to Malappuram, she joined a home nursing agency from where she received six months of training on post-delivery care and basic nursing tasks. As a postnatal care specialist, she used to earn between 25,000 and 30,000 rupees in 40 days. Now she makes less than Rs. 15,000 a month. Yet, she finds this as a more satisfying activity. She loves to take care of elderly patients and derives peace while serving them. She often feels sad about the residents of the elderly care home who have to live there even though they have adult children who are well settled. She also expressed her dream of starting a home nursing agency sometime in the future. Plate 2.1 shows the elderly residential home at which she works presently. Two of the residents of this institution are also seen in the picture.

Plate 2.1: An elderly residential care home and its residents



Source: Fieldwork

Good relationships that they establish with their clients is the most liked aspect, as per 16.67% of the sample. They feel happy about being there for the patients when they need them the most. Close to one-tenth mentioned it is the salary that the job fetches them that they liked the most about the job. A few informants revealed that they would not get a better job due to low educational qualifications. They find comfort in the role since it pays comparatively better than many other jobs. It also needs to be mentioned that a few HNs are ready to provide their services for free to the needy who cannot afford them. For instance, a caregiver named *Ajitha* says that she is willing to provide one month of free services for a destitute client.

Less than one-tenth rated taking care of babies as what interested them the most. All of these were women involved in postnatal care. About 5.33% viewed their relationships with their clients and families as the most rewarding aspect of their work. Most of the informants are happy and satisfied with several aspects of the job, including the service they provide to the ailing, the salary the job offers, the connections they build, and the experiences they have gained in the job.

A respondent named *Mary Suja* states that this job has enabled her to face difficult situations since she could interact with people from varied backgrounds. Because she has worked in places outside Kerala, she could learn new languages too. Most importantly, being an unmarried woman, she has learnt to become self-sufficient and economically independent.

Some HNs like the job for the fact that they are staying in a house that is a safe place. If the customers are good, then there would not be any concerns. They would have people to talk to and mingle with, which reduces the feeling of loneliness. A few were also happy about the good conditions and facilities at work.

Case - 14

Ushakumari is a 50-year-old woman who has been a home nurse for around twelve years. She has two married children, and her husband works as a mason. She had to begin working to support her family when they started experiencing financial hardship. Recently she switched to part-time as she wants to stay at her home.

Before shifting to domiciliary care, she worked as a hospital janitor. It is from the nurses there that she learnt different healthcare procedures. She feels that nursing is a job that suits women. Though she works for individual clients now, she has worked in elderly care homes earlier.

She considers serving the bedridden elderly as equivalent to involving in a spiritual activity. Providing patients with love and care, cooking for them, giving them timely food and medicine, and lending them an ear when they need attention are things she likes the most about the caregiver's role.

Case - 15

Joseph, a man in his early fifties, joined the Indian Red Cross Society's branch at Adoor in 2012, and he has been working with the institution since then. His family comprises his wife and their two daughters. He used to be occupied in agriculture and poultry farming before joining the home nursing field. The better salary this job offers motivated him. He is fond of the job and does not consider it challenging, despite nursing being a not-so-preferred choice for his gender. Since he was given training, he can accomplish most healthcare tasks, including physiotherapy. Joseph's relatives and friends know that he works for Red Cross as a caregiver. Some of them have appreciated him for undertaking this job.

In his opinion, the affluent sections of society do not take proper care of their elderly parents. They either admit them to nursing homes or hire a caregiver. He adds, "I cannot blame them. They work and earn money, spend it on the patient's care, and we accept that money as our salary. But since they hire a caregiver, it does not mean that they can back off. They are obliged to provide emotional support and affection to their ailing parents. Many adult children often forget this and consider the cared-for person as the home nurse's liability".

He views domiciliary care as a safer job option since a comfortable working environment and a homely atmosphere are available. However, he is concerned about the lack of freedom because the caregiver has to be available for the patient round the clock. He also expressed his

anguish that the job lacks social honour since most people regard home nurses as unqualified and untrained.

2.22.3 Disfavoured Aspects of the Job

An attempt was made to determine if the HNs did not like anything about the work. The informants were required to cite one aspect of the job they did not like. More than half of the respondents (51.33%) did not dislike anything about their job. While about 15% hated bitter relations with clients, demanding work conditions and work overload made their jobs less interesting for one-tenth. A little over one-tenth were concerned about the societal perceptions about home-based caregivers and highlighted the undesirable image that HNs have in society. Around 7% were worried about some patients' arrogant and inconsiderate behaviour. A few respondents mentioned harassment they faced from the clients/ their families and the difficulty staying away from their homes as the disfavoured part of their work.

2.22.4 Perception of the Work as Polluting

About 7% of the sample felt that handling the patients' excrement is polluting and wanted to avoid carrying out tasks like toileting the patients and changing their diapers. However, most informants who faced this difficulty in the initial days of their work later got used to it and now consider it part of the job.

2.22.5 Opinions About the Label 'Home Nurse'

As already indicated, the in-home care providers are known as 'Home Nurses' throughout the study area. It was decided to understand the care providers' opinion about the label and how

well they like to be referred by the term. Over 60% expressed that the job title is encouraging. While more than one-third found it neutral, it was a derogatory term according to 1.33%. Among the two informants who considered the label insulting, one is a man. Among the rest of the men, five found the label good, while 14 felt that it was neutral.

The respondents' opinions about their clients and relatives addressing them as Home Nurses was analysed. Close to two-thirds seemed to love being referred to by the term. More than a quarter viewed that it does not matter to them whether or not they are being known as 'Home Nurses'. Those who did not like to be called HNs accounted for 8 %.

As far as the male caregivers are concerned, six people like to be called a 'Home Nurse'. The label does not matter for ten respondents, while the other four did not like the label. Some of them declared that the term 'Home Nurse' does not suit men. One respondent added, "Nurse sounds fine, but the prefix 'home' does not sound good". Unlike some other male caregivers, *Sasi* likes being referred to by the 'Home Nurse' label. He says, "I have studied only till my Class tenth. After that, I could not continue my studies due to financial constraints at my home. Now that I work as a caregiver, and when people call me a 'home nurse', I feel happy. I have learned most nursing tasks from the hospitals where I stayed as a bystander. Without being academically qualified, the term 'nurse' is added to my designation. It gives me some status, and I take pride in that".

Interestingly, some nursing-qualified respondents suggested that they prefer a term like 'caregiver' to 'Home Nurse'. This could be to keep themselves distinct from the unqualified in-home caregivers.

2.22.6 The Positive Impact of the Label ‘Home Nurse’

It was analysed if the label ‘Home Nurse’ has had a positive impact on the caregivers’ lives or influenced them in any way. Though many indicated that their job made them more empathetic and tolerant, they had varied opinions on the job title. About a quarter felt that the label raises the value of the work they perform. For more than one-tenth, the term instils a feeling that their job is as good as hospital nurses’ job. Above two-tenths were happy being known as ‘Home Nurses’ since the label has saved them from being referred to as servants. A respondent named *Remya* says that the term itself gives a positive feeling since they are not maids. She adds, “If this title was not there, people would have called me as a maid or domestic help”.

About 8% who feel they have earned this name without completing any nursing training regarded the term ‘Home Nurse’ to boost their pride and dignity. A participant named *Susheela* commented that the label goes well with the caregiving task she does. She is aware that she should learn all healthcare tasks to make the title more apt. Nevertheless, about 7% (those who were less qualified educationally) perceived that the term was not apposite as they lacked the knowledge of healthcare procedures. Less than one-fifth viewed that the term did not have any impact since they were just neutral about its usage.

Few nursing qualified informants found the term to have positively influenced them. The label of ‘Home Nurse’ often pulls down their status. On the other hand, several respondents (especially those who have received some kind of training to accomplish healthcare tasks) feel that they are worth being called as HNs as they perform the duties a nurse is expected to.

Quite a few caregivers believed that our society does not correctly interpret the term ‘Home Nurse’. Hence, they like to be referred to as a ‘caregiver’, ‘helper’, or to be addressed by their names. For instance, *Mary Suja* says that the term ‘Home Nurse’ has a negative connotation.

Letting others aware that you are staying in a stranger's home invites scorn. This is the case generally for women, and particularly for unmarried women. She says, "Nursing is a good service, but when the context is a stranger's home, it altogether has a different meaning in the eyes of many people".

However, a few respondents do not seem bothered about this societal perception. A caregiver named *Sulatha* says, "There could be a bad perception about the job. But, we should not be vigilant of what others think of our job. We know what we are doing. We are earning money by working hard. We are not stealing anything, killing people or doing anything illegal to make money. We all should feel proud that we are doing a commendable service to the society".

2.23 Discussion

This chapter has depicted the socio-demographic characteristics of the home nurses, their work profile and perceptions about caregiving, their reasons and motivations to enter the field, and their prior work experiences. The caregivers' opinions about the label 'Home Nurse' have also been elaborated.

Over 85% of the 150 caregivers who took part in the research is female. This preponderance of women reflects the gender imbalance in the domiciliary care sector in Kerala. The ages of the caregivers ranged between 22 and 73 (Mean Age = 48.66, *S. D* = 36.06), and the greatest number was aged between 40 and 60 years. Caregivers who are Hindus accounted for over two-thirds, while Christians were around one-fourth of the sample. More than half of the caregivers were found to be educated below Class 10th. Graduates or academically nursing qualified people were only a handful. The average work experience of the caregivers is 7.61 years (*S.D.* = 6.57). Several caregivers were previously employed as daily wage labourers, cashew factory workers, clinic-

based nurses or hospital attendants, shopkeepers, hotel workers, or construction workers. As far as the healthcare training is concerned, more than three-fourths did not receive any kind of training from the nursing agencies they are associated with. In terms of the academic nursing background of the care providers, only about 15% were nursing qualified or trained to perform medical care tasks. However, many caregivers reported carrying out such healthcare tasks owing to their experiential knowledge, particularly while undertaking the role of bystanders during the hospitalization of their clients. The majority of the HNs have attended to elderly patients and others who suffer from chronic ailments or terminal illnesses. Around 20 postnatal care specialists are hired to render care to the newborn and its mother for a couple of months.

When it comes to their marital statuses, almost half of the informants were widows and divorcees. It is assumed that these numbers are a reflection of the liberty spouseless women have in choosing their occupation. The freedom to make decisions related to work due to the absence of husbands is one possible explanation for their numerical dominance in the sample. As far as the monthly salaries of these HNs are concerned, the average salary is Rs. 14,613 (*S.D.*= 2708). However, there exists a gender-wage gap since the male caregivers earn approximately 2500 rupees more than their female counterparts. It is worth noting that the job fetched better earnings for several caregivers as compared to their previous jobs.

The different job titles used for in-home care workers across countries have been discussed in the introduction chapter. However, there is no differentiation of the in-home caregivers in Kerala based on their expertise or nursing qualification. All the employees are referred to by the English term ‘Home Nurse’ and not by any equivalent *Malayalam* term. Though some home nurses exclusively provide domiciliary medical care, which is equivalent to the role of home health aides in the West, the majority works like home care aides / personal support workers as they attend to

household tasks and the patients' healthcare. Several female caregivers volunteered to help with chores even if the duty was not formally a part of their care plan. Most home nurses were content with the job title and acknowledged that it raises their dignity and confidence. Yet, the title was disfavoured by some academically qualified caregivers who consider it to downgrade their skills, a few male caregivers who regard it incompatible with their masculine identity, and some female caregivers concerned about the term's negative connotation.

The home nurses' ratings on the difficulty level of the job reveal that most of them consider their work easy or moderately easy. None of the respondents declared their job as very difficult. Correspondingly, satisfaction ratings indicate that none of the respondents is highly dissatisfied with their work. The majority seemed to be satisfied or very satisfied in their roles. The significant sources of satisfaction were the joy of serving the ailing elderly, the clients' contentment with their services, and the good bonds built with the patients and their families.

Similarly, the major factors that made the caregiver's role difficult are the nature of the patient's illness and the kind of relationships they share with the clients and their families. An important finding in this chapter is the statistically significant association between job satisfaction and difficulty levels. A Pearson correlation test revealed a strong negative correlation between the variables ($r=-0.688$), thereby attributing greater levels of job satisfaction to the ease of performing the job.

Research by Sims-Gould et al. (2010) demonstrates that "factors that attract individuals to become home support workers include previous experience, financial considerations, and the joy of working with people" (p.171). In the present study, factors that influenced to take up domiciliary caregiving are the job's relatively decent salary, personal or familial reasons, interest to look after the ailing, or a combination of financial considerations and some other reason. Some individuals

(mostly having faith in Christianity) who were drawn to the sector due to the love for serving the frail believed it was a virtuous act. For them, the satisfaction earned from work is more rewarding than the monetary benefits. A couple of male caregivers took up the role on the influence of their spouses who work in the same field. For some others, the salary and the ease of the job were the factors that attracted them to the job. There have been individuals who tried to end their lives since they did not have any source of income to support themselves and later landed this job. Some are proud of the excellent service they provide to needy patients, while others are grateful to the agency owners for employing them. Caregivers who lead complex family lives or lack familial support consider the job a liberation from their issues since it helps them get rid of boredom, emotional strain and loneliness. For such people, the job has offered psychological support besides financial support.

While some studies “conceptualized care work as a specific type of emotional labor, a few others highlighted the genuine emotional connection between the patient and the care worker” (Duffy, 2011, p.16). For instance, research conducted in New York by Chichin and Cantor (1992) found several care workers identify “psychological support offered to frail and isolated elderly as the main task they performed for their clients” (p.96). Similarly, home nurses in the present study value emotional support and assistance they render to their clients even more than or as much as the performance of nursing procedures. According to them, the most-needed qualities of caregivers ordered in a hierarchy are patience, interest to look after the ailing, commitment to the job, cleanliness and hygiene, and the ability to accomplish healthcare tasks. The home nurses’ genuine interest to serve ailing elderly has been illustrated with the aid of a few case studies. The aspect will be elaborated in Chapter 5, which unravels the relationships between the caregivers and the cared-for persons.

As far as the home nurses' perception of their job is concerned, the worth and significance of the work led many to consider it a laudable service. Nevertheless, they are aware of the job's marginal status due to the negative connotation and stigma attached to it. Not making their work identities public is an open testimony to this. Since their work is all about touching human bodies and often includes dealing with human waste matter, they are worried that society limits their role to these aspects alone. Twigg et al. (2011) argue that body work is "sometimes a form of dirty work in both the literal and sociological senses as workers have to negotiate the boundaries of the body and deal with matter out of place" (p. 172). However, less than one-tenth of the home nurses in the present research agreed that they ever felt the work was dirty and polluting. Research has identified aged bodies as specifically polluting because they have "piled up undischarged remnants of a lifetime of eating and drinking, and thus perceived as particularly dirty, open, unlimited and unattractive" (Twigg et al., 2011, p.178).

While discussing the low status of care workers, Aronson et al. (2004) opine that the disregard for the job can be "associated with the needs of elderly and disabled people who are themselves held in low social regard and because it is undertaken out of public view in people's homes" (p.112). Though the above-said categories of patients might have low social standing, caring for them has been cited as one of the best-liked aspects of the job by a substantial number of home nurses in the current study. Analysis of the most disliked aspects of the job reveals that more than half of the caregivers did not find any faults with their jobs. The remaining were found citing matters such as bitter relations with clients, demanding work conditions and work overload, the societal perceptions about home-based caregivers, inconsiderate behaviour of some patients, and ill-treatment or harassment they faced from the clients/ their families.

The sex-typing of jobs and the tendency to regard care work as women's speciality has already been dealt with in the introduction chapter. Most of the informants, barring a few male caregivers, seemed to support this view. These men stated that caregiving should not be limited as suitable to one gender. However, all the female caregivers considered nursing a career ideal for women due to their gender roles and the ease of performing it.

England's (2005) work on 'theories of care work' discusses different perspectives associated with the job. The 'devaluation' perspective underlines that cultural biases hinder not only wages but also state support for care work due to its association with women (pp.381–382). However, the present research participants do not link this gender association to the lowered status of their job. Another framework titled the "prisoner of love" highlights "altruistic motivations for and intrinsic rewards of care work and that these may lead care workers to accept low pay" (England, 2005, p.382). This framework is supported by the findings of Lightman and Kevins (2019), who argue about care workers' "better job satisfaction than equivalent workers outside of care work, due to the impact of nonpecuniary benefits such as helping others or building relationships with clients" (p.12). In the present study, this perspective is exemplified in the case studies of *Binoy*, *Kumari*, and a few others who left better-paying jobs and continue in domiciliary care for the rewarding experiences it offers. On the contrary, there is the "commodification of emotion" framework, according to which "care work generates additional stress and/or alienation for the worker, thereby resulting in lower job satisfaction" (Lightman and Kevins, 2019, p.1). However, the present study findings do not support this framework.

The following chapter explores the role of nursing agencies in the domiciliary care sector in the study area.

Chapter 3

Home Nursing Agencies: Facilitators of the Care Services

3.1 Introduction

This chapter discusses the case of home nursing agencies that act as the intermediaries in the private home care industry in the study area. As stated in the introductory chapter, Kerala has seen a proliferation of clients needing residential care services in the past few decades, and the increasing number of nursing agencies in each district affirms this fact. The majority of these agencies are run by private entrepreneurs. With the help of the staff they recruit, these agencies make home healthcare services available round-the-clock for their customers. The care needs of the clients vary, so do their requirements. While some hire home nurses for elderly care, several others need them for the care of newborns in their families. The services are also sought for patients who do not have any severe physical illness but require emotional support or housekeeping assistance. The clients who do not require live-in caregivers hire employees part-time.

The findings presented in this chapter are based on the data gathered from the owners of 24 home nursing agencies located in different parts of the districts in southern Kerala. The participants were probed about the services delivered by their respective agencies, the criteria adopted for selecting caregivers, the training offered to their staff, terms and conditions related to employment, and their role as mediators in the home-based care industry in the state. Throughout the chapters, they are referred to as ‘agency owners’, ‘agency managers’, or ‘agency directors’. In this particular chapter, they are also referred to by the terms ‘respondents’, ‘informants’ and ‘participants’. In a couple of cases where the owners were unavailable, the agency office staff

provided the information. For convenience, the home care agency is mentioned as ‘agency’. The caregivers are referred to by the term ‘Home Nurses’ and its short form ‘HNs’.

3.2 Nursing Agencies: Ownership and Background

Interviews with the agency owners started with questions on the agency’s history and its owner’s experience in the field. It was decided to identify if the agencies are authorised by the state government, if the agency owners had any background in nursing, if the agency had branches all over the state, and if they were motivated to start the agency for non-profit motives.

Among the home care agencies, only five were relatively newer in the field. The rest had more than five years of experience in the home-based care industry. Out of these, fifteen were established before the year 2010. An agency located at Muvattupuzha in Ernakulam district has been functioning since 1999 and is the oldest one in the sample.

All the agencies are reported to have registered themselves with the state’s Department of Labour and, thus, licensed to run the business. The registration numbers are also included in the agencies’ office records, nameplates, hoarding flexes and visiting cards. Besides this registration, some agency owners have memberships in state-wide associations for home nursing agencies, such as All Kerala Placement & Home Nursing Services Association (AKPHSA) and Home Nursing Service Owners Welfare Association.

Nine of the 24 agencies have their branch offices located in other districts or other parts of the same district. Eight agency owners run other businesses. This includes three people who own elderly residential care homes, and the others are into enterprises like beauty parlours, textile shops, job placement agencies, and psychological counselling centres.

The agency managers' familiarity in nursing was probed to elicit if they or their spouses are academic nursing qualified, and the interest in starting a home care agency is an outcome of it. Two-thirds of the managers mentioned that neither they nor their spouses have any background in nursing. Ten people stated that they started nursing agencies since they felt that the home nursing industry is mushrooming in Kerala as the number of people availing of formal caregiving services is much greater than before. Four others mentioned that they wanted to create employment opportunities for needy women, and an agency owner among them runs a psychological counselling centre parallelly. He reports having advised two women who tried to commit suicide and a few others who did not have any other source of livelihood to start earning by working as HNs. This agency owner is content that he could bring back these people to life by offering them a source of income. Another agency manager was moved by the plight of women who have abusive relationships with their drunkard husbands. He stated that he takes pride in aiding several such women to become financially independent and lead their lives in dignity. Four respondents were motivated by the desire to provide care for patients in need. Three agency owners ventured into the field to find a source of income since they were not satisfied with their previous jobs. These agency owners are happy that their business is not only doing well but also offering great service to their clients. The remaining three mentioned that they were influenced by their religious values and the virtue of being compassionate. They added that they have been passionate about providing care to the ailing (especially the elderly) and improving their lives. Though the business generates some profit, they stated that their primary goal is the wellness of their clients and the creation of employment for the caregivers. It is worth noting that all the three agency owners follow Christianity and believe in the ethic of serving humanity.

3.3 Advertisements of the Home Care Agencies: Strategies to Gain Popularity

Since there has been increased competition in the home care industry, each home nursing agency tries its best to publicise its services and attract more customers. Information about means and ways to advertise their services was gathered from agency owners.

The business cards of the agencies that took part in the study were collected. Particulars such as the name, address, registration number, information about the different services provided, and contact details of the agency are included in them. Most of the cards have images of nurses taking care of elderly patients, pictures of motherly affection for representing postnatal care services or images of nurses in uniforms. The logos of some of the agencies had elements that represent care and affection. It was observed that the agency owners who run two businesses used both sides of a card to advertise their businesses. The business card of some of the agencies are given below (Plate 3.1). One of them belongs to an agency whose managing director also owns an elderly residential care home.

While some resort to the conventional methods like newspaper advertisements, circulation of pamphlets and promotion by word of mouth, the others use online advertisement platforms. A couple of agencies maintain an active online presence through their websites. In the online advertisements, the array of services provided by the agency and the nature of care provided by their staff are emphasised. The agencies claim that they offer expert caregivers who are well experienced and trained in various healthcare tasks. Their staff's trustworthiness, warm and friendly behaviour, and cleanliness are accentuated qualities. The staff is portrayed to be possessing a complaint-free record. A couple of agencies mentioned the busy schedules of their clients' family members who are employed in different professions in the government and private sectors, due to which it becomes difficult for them to manage caregiving and household affairs.

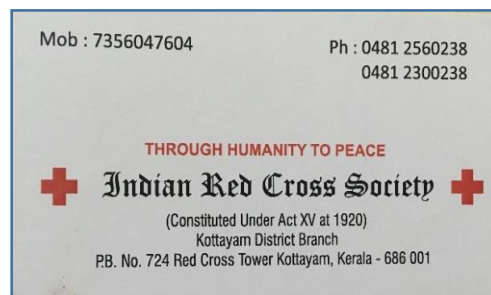
Here, the home nurses become a helping hand to them by providing care to the ailing relatives and incapacitated dear ones. Some advertisements also contain the information that care providers can help with household chores as per the clients' demands.

To affirm that their staff does not have any criminal records, some agencies include the point that their team is recruited after conducting a proper background check.

Besides the advertisements that target the clients, the agencies also include information about job hiring. In such cases, they discuss the requirements by stating the kind of behaviour expected from a caregiver. Most often, the kind and compassionate nature of the person is preferred to the ability to perform health care tasks. That is why some of the advertisements mention that professional training and practice given to aspiring caregivers do not suffice, but empathy towards the sick and patience to withstand difficult situations matter equally. The job hiring posters also emphasise the significance of providing solace and support to the suffering patients. The good work that a care provider does is considered a divine act and, thus, an invaluable service. Some agencies also added that they would train their staff to deal with patients who belong to different age categories and suffer from varied illnesses.

As per the commercials, most agencies' services include elderly care, post-surgical care, neonatal and post-delivery care, and physiotherapy. The duties and responsibilities of the home nurse include nursing the patients with care and affection, providing medicines at prescribed timings, monitoring their health conditions, feeding the patients, helping them with all personal care needs, dealing with urinary or faecal incontinence, and maintaining the cleanliness of patients' rooms and washroom.

Plate 3.1: Business cards of some home nursing agencies



Source: Fieldwork

3.4 Understanding the Workforce: Home Nurses and Their Services

An attempt was made to identify the size of the nursing agencies by inquiring the number of home nurses associated with them. Since some agencies cited that they have employees who are not regularly working, the number of HNs who are currently working was considered. More than half of the agencies (58.34%) have less than 100 HNs working for them. While four agency managers stated that the count is between 100 and 200, four others seemed to have more than 200 HNs. However, the remaining two did not provide a specific number. This could have happened either because they are unaware or do not want these details to be transparent.

The family backgrounds of the staff, as stated by the agency owners, reveal that the majority belonged to economically backward families and took up the work to keep their lives going. A few narrated the personal issues of some of their staff that led them to begin working as caregivers. These issues include financial difficulties and debt, loss of a previous job, death of a life partner, abuse of an alcoholic spouse, and chronic illness of a family member. However, a couple of owners cited that they employed some HNs who wanted to be in the field for altruistic motives, mentioning their interest in serving patients.

It could be known that the caregivers belong to different religions and castes. All the agency owners stated that most of their staff are Hindus and Christians. While a few agencies had a handful of Muslim employees, the remaining did not have any Muslims. All the respondents were of the view that people belonging to lower castes or backward castes accounted for the majority of their Hindu employees. The presence of people belonging to higher castes such as *Nair* and *Pillai* in insignificant numbers was noted by some of the respondents. The agency owners' awareness about the HNs disguising their caste/ religious identities from the clients was explored. While two respondents stated that most of their staff disguised their castes, twelve others believed that only

some of their staff did the same. The remaining ten were unaware of this aspect. The ones who knew that their staff concealed their caste affiliations stated the fear of discrimination as the reason for this step. An agency manager recalled an incident where an HN was mistreated by a high-caste family. *Kunjamma*, an agency office staff feels that some of the customers' attitudes towards the HNs should change. The HNs deserve to be treated better and respected for their work. She is unhappy that several customers discriminate against workers from lower castes. Some demand that they do not want people of castes like Paraya and Pulaya. She laments, "Some clients want the HNs to deal with the patients' excrement, but they will not let these people touch their food".

The caregivers and the office staff keep their employment details a secret from their kin. Out of the three office staff interviewed, two mentioned that they did not want their relatives to know where they had worked. *Kunjamma* mentioned above was one among them. She has been working in an agency for more than five years now. She had informed others that she worked in a shop nearby the agency office. She did this due to the misperception that female home nurses are sexually promiscuous. She felt that people do not value the job of caregivers. They believe that these home nurses are useless, so they are ready to touch the human waste of another person. She stated that she was made to think the same, but after a couple of years, she realised the value of the caregivers' role. She learned from her experience that HNs are doing an excellent service to the patients by taking care of things even their kin refuse to do. She further added that this realisation made her proud in disclosing her job as a nursing agency staff.

When it comes to the type of employment, 17 agencies facilitate both full-time and part-time for HNs. The remaining seven solely supply full-time home nursing services. The part-time HNs work till five in the evening and leave the clients' homes. It was identified that some of the agencies deliver the services of housemaids and babysitters. While six agencies are exclusively

the providers of home nurses, 13 others provide both home nurses and housemaids. The remaining agency owners had home nurses, housemaids, and babysitters on the employee list. A couple of informants pointed out that some of their HNs undertake the work of housemaids when they do not get the job as HNs to meet the ends.

Details about agencies undertaking inter-district and inter-state contracts were enquired. Twelve agency owners let their staff work in other districts, whereas six sent their employees outside Kerala. However, the remaining did not allow their staff to work outside the district. It was noticed that none of the agencies sends their HNs abroad.

Since many migrant labourers in Kerala are involved in different sectors, the agency owners were asked if they have any employees hailing from other states. While 17 agencies did not have any, six others have workers who belong to states like Tamil Nadu, Andhra Pradesh, and Odisha. One agency manager recalled that there used to be some such staff earlier.

Table 3.1: Number of HNs registered with the agency

Number of home nurses registered with the agency	Numbers and Percentage (in parentheses)
Less than 50	7 (29.17)
50-100	7 (29.17)
100 to 200	4 (16.67)
More than 200	4 (16.67)
Cannot specify the number	2 (8.33)

3.5 Understanding the Clientele: Care Receivers and Their Background

The agency managers were queried about the backgrounds of their clientele to identify if there are any trends concerning the religious affiliations of their clients, their financial condition, the illnesses for which services are sought, and their requirement and conditions regarding the employment and employee. By probing the clients' religious backgrounds, it was intended to identify if any particular community utilizes home services more than others. It could be due to the numerical dominance of Hindus and Christians in the study area (in comparison to Muslims) that some of the agencies had an all Hindu, all Christian, or a combination of Hindu and Christian clients. However, more than half of the sample (58.53%) have clients belonging to all the three dominant religions of the state. It was also explored if the clients prefer employees who belong to their own communities or do not want employees who belong to a particular caste/ community. Only one of the agency owners stated that none of their clients was particular about the employees' religious affiliations. Seven people indicated that Muslim clients wanted HNs from the same religion. While two agency managers revealed their clients' disinterest in hiring Muslim HNs, the remaining 11 mentioned that a few employers want neither people belonging to SC/ST categories nor Muslims. These clients were concerned about the cleanliness and hygiene of the employees, and they perceived that some of the lower castes were less clean. The agency owners also opine that several Hindu clients expressed their difficulty adjusting with Muslims, due to which they preferred Hindu or Christian workers.

It was known that several customers that avail home care services also want the caregiver to help them with domestic chores such as light housekeeping and doing the dishes. This is in addition to the activities related to the patients, such as preparing meals for them, doing their laundry and accompanying them whenever they have to travel. In cases where the caregivers'

assistance is required for other household activities, the clients inform beforehand and pay the agency a few thousand rupees extra. However, there have been cases of clients not paying this amount and making the caregiver perform extra work, added an agency manager. This aspect was brought to the agency's notice by the HNs, and the agency owners ensured that the workers were recompensed duly for their time and effort. Only four of the 24 agency owners believed that most customers hire the HNs to perform caregiving tasks alone. Several agency owners state that their staff is not much equipped to deal with the medical tasks, though all of them can assist the patients in their personal care needs. An agency owner named *James* commented that fortunately, a substantial number of their clients ask for the caregiver's help with the latter. Nevertheless, he adds that the ability to perform medical care tasks gives the home nurse an upper hand, which would enhance the respectability of the job. It is worth noting that some agency owners believe that home nurses should assist the clients' family members since this would indirectly help them care for the patients.

The agency owners' understanding of their clients' selection criteria for choosing the caregiver was explored. The respondents were required to cite the major criterion/ criteria the clients use. Nine people mentioned that aspects such as their physical fitness, patience level, honesty, educational qualification, and commitment to providing care are the clients' priorities. Six others mentioned all the above factors except the educational qualification. Out of the remaining respondents, five mentioned that the cleanliness and personal hygiene of the HNs are the most sought-after qualities of the caregivers. Only one agency manager cited the sameness of caste as the primary selection criterion.

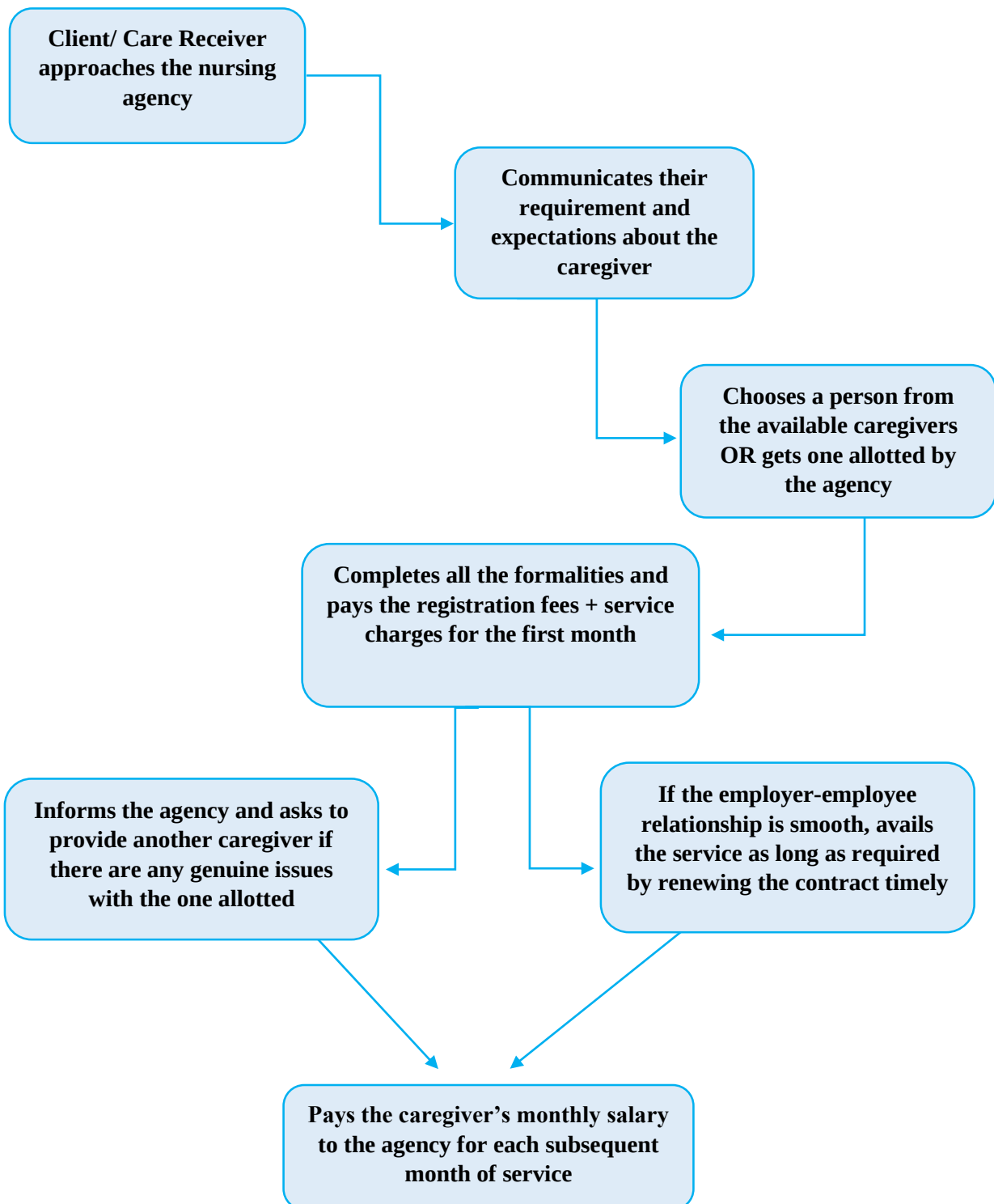
Analysis of the major illnesses of the patients seeking caregiving services reveals that geriatric care is the main requirement of the greatest number of clients. In several cases, home

nurses are hired to care for elderly who are bedridden or have ambulatory difficulties. Quite a few clients were reported to be facing cardiovascular issues and musculoskeletal diseases. A couple of agency owners mentioned mental health issues associated with old age, such as memory loss. Chronic illnesses like cancer, Alzheimer's disease, stroke and Parkinson's disease that lead the patient to become dependent on others to get their daily needs done were cited by twenty respondents. Eleven respondents among these mentioned postnatal care also as a service that has a high demand. It was also identified that the HNs working for most agencies are not selectively allotted to people suffering from a particular illness. The only difference is the case of postnatal care specialists who are trained to attend post-delivery cases alone. Twenty two agency owners did not mention any disease-specific allocation of their HNs except for postnatal caregivers.

Table 3.2: Major illnesses suffered by clients

Major illnesses of the clients	Numbers and Percentage (in parentheses)
Geriatric care	3 (12.5)
Geriatric care + postnatal care + Illnesses such as cancer, heart diseases, stroke	10 (41.67)
Geriatric care + post-natal care	1 (4.17)
Geriatric care +Illnesses such as cancer, heart diseases, stroke	10 (41.67)

Figure 3.1: How a new client avails home nursing services from an agency



3.6 Choosing the Caregivers: Selection and Recruitment of the HNs

The agency owners' selection criteria employed in the recruitment process were analysed to understand if they set any staff recruitment standards. The majority of the agencies did not consider the educational qualification or the work experience of the HNs before hiring them. Seventeen agency owners stated that physical fitness, interest, and ability to work are the qualities they look for in prospective employees. Only four respondents indicated that they consider their employees' educational backgrounds. While two agency owners hired only those who are known to them personally, one other had no standards as such. Only one of the agencies followed some kind of test to analyse the employees' ability to perform healthcare tasks. However, all the agency owners reported their existing staff making referrals to hire their relatives and friends interested in working. A few agency managers highlighted some mother-daughter duos, mothers-in-law and daughters-in-law, or sisters working for them. One of the informants remarked that they have four people from the same family registered with their agency.

It was found that every agency had some criteria for selecting their male and female workers. All the agency owners stated that they look for married female employees since most clients are not likely to hire unmarried women. This being the case, the marital statuses of the caregivers also revealed that only a handful of unmarried people work in the sector. When enquired about the selection criterion for male caregivers, 21 respondents stated that they like to employ men who are teetotalers. The remaining three were owners of agencies that do not employ male caregivers.

It was analysed if the agency owners considered the educational qualification of their staff or preferred employees who have acquired a certain level of education. The majority did not follow

any such criterion. The response of an agency manager is worth quoting here. He questions, “why do we need educated people to deal with human waste? Do you think educated people will come for this job unless their situation is so bad?”. This statement testifies that even the people associated with the home care industry do not value other aspects of the work that the caregivers perform but limit the nature of work to dealing with the patients’ excrement.

Only one of the agency owners mentioned that they chose nursing qualified or nursing trained people, while three others preferred staff who are at least Class X passed. One of these three people opined that though they have a criterion, it is a flexible condition since finding educated workers will be difficult in cases of urgent requirements. He states, “We try to look for people who are better qualified. But we cannot always find such people, so the educational background is not a benchmark. Moreover, to work as a care provider, one has to possess several other qualities that are more important than education”.

It could be known that all except one of the agencies follow a similar recruiting procedure. They obtain an undertaking from the HNs, collect their identity and address proofs, and take the references of any two people from the HNs’ locality- preferably someone associated with their local self-government bodies. The only difference is that one of the agencies’ procedures require their staff to submit a police clearance certificate from their local police station after their background check is completed.

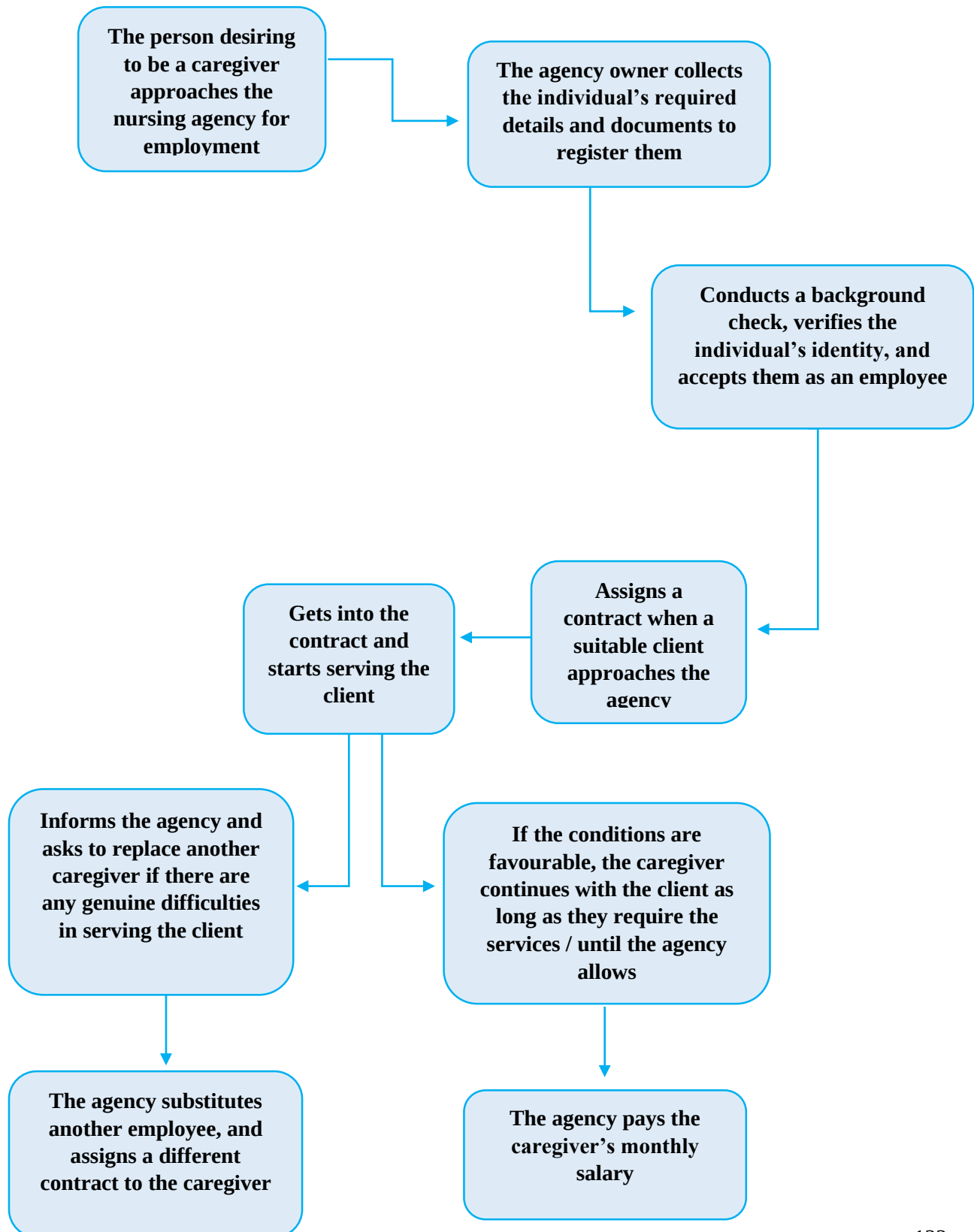
Table 3.3: Criteria for the selection of employees

Agency's selection criteria	Numbers and Percentage (in parentheses)
Educationally qualified people are preferred	4 (16.66)
People with a healthy body and interest in work	17 (70.83)
People from personal contact/ circle preferred	2 (8.33)
No criteria as such	1 (4.17)

Table 3.4: Educational criteria for HNs

The minimum requirement concerning education	Numbers and Percentage (in parentheses)
Class X	3 (12.5)
Class XII	0 (0)
Nursing qualified/ trained	1 (4.17)
Education is not a criterion	20 (83.33)

Figure 3.2: Selection and recruitment of a caregiver by the nursing agency



3.7 Analysing the Caregivers' Salaries: Instances of Gender-Wage Gap?

The caregivers' salaries were expected to vary between and among the nursing agencies. An attempt was made to identify if the salaries of the employees are uniform and explore the factors that influence variation exists. Though the wages are more or less similar across the different agencies studied, the pay for men and women differ in many cases. The postnatal / delivery care providers are generally paid higher than the HNs who render care for other illnesses. This is because the former have to attend to both the newborn and the mother, which takes more time and effort. The respondents were requested to provide details of the average salary paid to their staff. Nine agencies were paying a monthly salary of about 10000 to 12000 rupees to their female caregivers, 13000 to 15000 for males, and above 18000 for those involved in postnatal care. All the remaining agencies were remunerating about 12000 to 15000 rupees for their female HNs, 15000 to 18000 rupees for males, and above 20000 for postnatal caregivers. It should, however, be noted that the amount charged by the agencies from their customers is approximately 2000 more than what the caregivers are paid. This amount goes to the agency in the name of management cost, which is generally considered the agency's commission for making the services available to their clients. This commission is charged every month, whereas the registration fees have to be paid by the customers when they initially sign a contract.

The difference in the salaries of male and female caregivers implies that gender is a deciding factor. However, only one of the respondents believed that the caregiver's gender influences their salary. Four agency owners stated that it is the patient's gender that is considered, and the caregivers of male patients are paid more since their caregiving process is believed to be more challenging. All the remaining agency owners opined that both the patient's illness condition

and gender affect the caregiver's salary. The patients who suffer from severe illnesses and need more effort on the caregiver's part would be charged a few thousand rupees extra compared to patients who require a lesser level of assistance. The caregivers' educational qualifications or academic nursing background do not seem to impact their salary.

Table 3.5: Remuneration of HNs

What is the remuneration of the home nurses? (in thousands)	Numbers and Percentage (in parentheses)
10000 to 12000 for women, 13000 to 15000 for men, above 18000 for pregnancy care	9 (37.5)
12000 to 15000 for women, 15000 to 18000 for men, above 20000 for pregnancy care	15 (62.5)
Above 15000 for women, above 18000 for men, above 25000 for pregnancy care	0 (0)

Table 3.6: Factors that influence remuneration (excluding postnatal care)

Factors that decide the remuneration (excluding postnatal care)	Numbers and Percentage (in parentheses)
Educational qualification	0 (0)

Gender of the home nurse	1 (4.17)
Type of illness the patient is suffering from	0 (0)
Gender of the patient	4 (16.67)
Spending capacity/ spending power of the client	0 (0)
The qualification +gender of the home nurse	0 (0)
The qualification +gender of the home nurse+ type of illness of the patient	0 (0)
Gender of the patient + type of illness of the patient	19 (79.17)

3.8 Employee Benefits: Do Agencies Go that Extra Mile for their Employees?

It is widely believed that offering employee benefits besides the monthly wages impacts the success of a business positively. Employee benefits help companies not only to attract good employees but also to retain them. Especially in industries with much competition, providing benefit schemes to employees helps businesses gain a competitive advantage. Since home-based care belongs to the unorganised sector, it is assumed that there are fewer chances of the employees

being entitled to provisions such as pensions, provident funds, or insurance schemes compared to the organised sector employees. To gain clarity on this aspect, the agency owners were enquired about the benefits they provide to their staff. It was found that none of the agencies provides any kind of benefits for their employees, be it life insurance, medical insurance, or any other welfare scheme. However, a few of the respondents cited that they have a system of paying a bonus to their employees once a year- mainly for the state festival season of Onam. The employees are given an additional amount apart from their month's salary during this time. The only benefit most agencies provide to their staff is paid time off. The employees are entitled to two paid holidays per month to visit their families. Nevertheless, a few informants cited that some HNs prefer to stay in the clients' homes even during the holidays. This is either due to the bitter relationships with their family members or the fear of leaving alone their elderly clients who do not have co-residing relatives. The agencies that do not offer paid time off let their staff either use the two days for personal matters or work and get paid for those days.

3.9 Employee Retention: Do the Agencies Have Strategies to Retain their Staff?

Like many other jobs in the unorganised sector, a greater number of employees are expected to quit the home nursing field due to several reasons, including the lack of benefits mentioned above. To understand the employee retention and turnover rates, the agency owners were surveyed how long their employees remain with them. The findings suggest that several respondents could not specify a period since it varies from one employee to another. According to nearly half of the respondents, some employees stay for months, while the others stay for years together. The remaining respondents expressed difficulty estimating the duration as the employees' natures are unpredictable. One of the agency owners has seen people leaving the job

within the first week, while many others have been associated with the agency for decades. As cited by the agency managers, the reasons for the employees quitting their jobs include difficult work conditions at the clients' homes, lack of freedom, isolation from family members and coworkers, getting better job opportunities, and ill health that restricts performing arduous physical tasks. Nonetheless, disappointment with the salary was not mentioned as the reason by any respondents.

3.10 Satisfaction with the Staff

The agency owners' satisfaction with the employees they hired was examined. While seven people seemed to be very satisfied, all the rest stated that satisfaction depends on the nature of the employees. The latter did not generalise since there are two categories of employees: the ones who are sincere and dedicated to their work and the ones who create trouble for the agency owners. One of the agency managers opined that "some HNs are so much in need of money that they will be ready for whatever adjustments". He hinted at the existence of caregivers developing illicit relationships with the clients/ their relatives. He added, "Their situations prompt them to do things that are otherwise immoral. But we cannot blame them fully". However, none of the respondents stated dissatisfaction with their employees.

3.11 Training Provided to the HNs: Are the Caregivers Prepared Enough?

Across the state, it is believed that not all the people who work as home nurses are equipped with nursing care tasks that they are expected to perform. Since the majority of the workforce in the industry is not highly educated, customers often blame the agencies for not properly training

their staff. It was decided to identify if the informants provide their employees with adequate training and understand the sort of training provided. All the agency owners believe that they are responsible for providing training and supervision to their staff to facilitate them to perform well in the contracts they undertake. It was found that the number of agencies that offers training to their staff almost equals the number that does not. The former was asked about the kind of training given to their employees, and it was found that seven agencies equip their HNs with the knowledge to perform the various healthcare tasks. While three others focus on occupational socialisation, only one of the agency owners indicated that their employees are given training on healthcare tasks and occupational socialisation. By occupational socialisation, they meant the kind of awareness a person needs about the job, such as the importance of caregiving, the work expectations, and the manners they should follow at the workplace. A few agency owners who do not impart training on healthcare tasks justify their position by stating that they send their staff as hospital bystanders, and in such cases, they will be able to learn the healthcare procedures directly from the nurses and doctors. Two agency managers revealed that some clients are willing to explain these tasks to their HNs, thus not bothering about the training part. One of the informants thought that offering training is a waste of time and money since there is no guarantee that the employees will remain with the agency for at least a couple of years.

The training provided by the agencies differs, which is reflected in the varying durations of the training. The majority reported conducting only a one-day training class annually, for which all their staff is advised to attend without fail. Though three agencies were holding a one-week training program, just one agency, namely, Red Cross Society, provided extensive training that lasted for more than a month. It was the Red Cross Society that did so. The manager of the society's branch stated that they used to give months of training to its employees earlier. However, now they

have limited the training to first aid classes and procedures like a sponge bath, bed making, insulin administration, tube feeding, and urinary catheter maintenance. The training classes organised by the agencies include imparting theoretical knowledge and practical sessions that demonstrate the nursing procedures. While three agency owners stated that they provide the training themselves, all the others were approaching doctors and nurses working at government hospitals or nursing students. The Red Cross Society mentioned that their training classes are mainly instructed by nurses who work at the nearby Government Medical College. Some of the agencies also sought the help of their own employees who are academic nursing qualified.

3.12 Gender-based Allocation of Staff and Caregivers of Male Patients

To understand if the caregivers are allocated based on the patients' gender, the respondents were asked if they allow their staff to take up contracts with clients of the opposite gender. Like the general trend, the care of female patients is earmarked for female caregivers. However, female caregivers are often employed for patients of the opposite gender even though male caregivers work exclusively to care for patients of their gender. All the agency owners mentioned that their customers have several times sought after female care providers to look after their ailing male relatives. Despite the common belief that women are better caregivers than men, none of the respondents provided this as the reason for the preference of female HNs. 15 respondents opined that female caregivers are chosen considering the safety and security of the women in the clients' families. The agency owners find that hiring a man to work as a full-time care provider does not seem to be a safer option for such clients. Another five respondents stated the fear of male HNs being alcoholics and smokers worry the clients, and they seek female caregivers instead. As per the remaining four, aspects such as women adjusting better than men with the work environments

and their contribution to household chores served as reasons for the clients to choose them over their male counterparts.

It was explored if the female caregivers of male patients get paid on par with male caregivers. Seventeen agency owners paid both genders equally for the same work. Three agencies that did not have male employees indicated that the HNs who care for male patients get paid more than those with female patients. The other four agency owners paid their female HNs less. As a reason for this disparity, one of the agency managers stated that women should not be paid more or at par with them as they will become arrogant. He takes his stand and states that “Men are always above women; they should be paid a little more even if it is for the same work”. This attitude throws light on how the agency owner propagates the idea of unequal pay, thereby supporting sexism.

When the issue of male caregivers’ scarcity was probed, seven agency owners did not seem to face any difficulty finding male employees. While fourteen respondents expressed that male HNs are insufficient, the remaining three did not hire male caregivers. Even if several clients prefer female HNs for male patients, many are particular about having a male caregiver. Given this, the agency owners were requested to explain what they would do when there is a shortage of male HNs in the agency. While 11 informants would try to convince the clients and allot female HNs, ten others would search and find male caregivers. Out of the three agencies that hire only female workers, two opined that their clients understand that they do not have male employees and thus hire female employees as a substitute. The remaining one stated that the agency would not compel the clients to hire a woman but refer the client to another agency with male care providers available.

All the agencies except those that do not hire male HNs pay their female employees less than their male employees. The salary of women who take up contracts of male patients is already

discussed. Out of the 21 agencies that have male employees, 17 revealed that the male caregivers demand a higher payment than their female counterparts. Also, only seven of these 21 agency owners believe that the male HNs are educationally better qualified than females. Those who expressed this thought stressed that many male caregivers could perform physiotherapy. Quite a few respondents view that men are only a handful in the profession, and to retain them, they need to be paid better. Their salaries are not often compared to female caregivers but to men who work for daily wages. “It is considered unfair to pay men lesser than what they deserve”, opines the managing director of one of the agencies. More than half of the informants find that men have to be paid more since that is the general trend. Some believe that men deserve greater pay for looking after male patients, which is a riskier and a demanding job. A few others did not forget to mention that men have more expenses for food and other day-to-day requirements, but women typically adjust with whatever facilities they get in the clients’ homes.

3.13 Duration of the Contracts: How Long Can a Caregiver Work for a Client?

The agency owners were enquired about the maximum period for which they would allow a caregiver to work for a particular client. Ten respondents permitted the contracts to continue as long as the clients wanted. Four agencies let their employees in a particular contract up to 3 months while two others allowed a maximum period of 6 months. While four respondents stated the duration could be up to a year, the remaining three could not specify the period. However, several respondents expressed their apprehension about the clients entering into direct contracts with the HNs, thereby making the agency lose its place in the system.

Table 3.7: Duration of the caregiving contracts

Duration of a contract	Numbers and Percentage (in parentheses)
Less than a month	0 (0)
1 to 3 months	4 (16.67)
Up to 6 months	2 (8.33)
Up to a year	4 (16.67)
As long as the client wants	10 (41.67)
Cannot specify	3(12.5)

3.14 Managing the Caregivers and Care Receivers: Agencies' Rules and Regulations

Since they are the mediators between the care providers and service users, the agencies have to see to it that they do their best to avoid conflicts between both categories. In case of any issues between the clients and the HNs, the agencies interfere and try to resolve the issues in a manner that does not harm either party. However, as reported by the agency owners, there have been a few instances where they could not sort out the issues and hence had to seek the help of the police.

To ensure the smooth functioning of the agency, the owners have framed a set of instructions both for their employees and customers. The researcher could get copies of the instructions from 12 agencies. The rest either were not interested in providing it or did not have it in handy at the time of the interview. A copy of the instructions for the employees from one agency,

a copy of the instructions for the customers from four agencies, and copies of both from seven agencies were obtained. The instructions are more or less the same across the agencies and are given below. However, the differences that were identified are also included. The instructions were printed in Malayalam, and the researcher translated them into English.

An agency located in the Kottayam district has a more extensive instruction booklet (Plate 3.2 has its cover page), while the others have a 2-page pamphlet. This agency begins the instructions with a few lines that describe what the service means to them. They state, “Providing bedside care and showing love and affection to frail elderly, bedridden patients, and other people who suffer from illnesses is what is meant by home nursing. Home nursing service scheme chooses and offers training to young men and women who are capable and willing to provide the service”. The gist of different sections of the booklet, namely the rules for employers, terms and conditions regarding the service and salary of the HN, and the rules for the HNs, are as follows.

3.15 Guidelines for the Employers

- Employers can avail the services of home nurses for patients who are hospitalised or homebound.
- The HN will be sent for employment only with a female relative of the patient (preferably someone who co-resides with the patient).
- The service is usually provided for patients who suffer from the challenges of ageing and other bedridden patients who require assistance with the Activities of Daily Living (ADL). Employees cannot be hired for hospitalised patients admitted in general wards or rooms shared by multiple patients.
- Female nurses will not be assigned for male patients less than 80 years old. Male nurses are available for taking care of such male patients.

3.16 Instructions About the Services and Duties of the Home Nurse

- As instructed by the doctors, home nurses have to provide timely food and medicine to the patients.
- Read out the newspapers or holy scriptures if the patient wishes.
- Love the patient and provide care for them like kin and keep the patient happy. Carry out the service with a sense of responsibility.
- Home nurses are in charge of all the ADL tasks besides taking care of bed making, cleaning the rooms and washrooms of the patients.
- Home nurses are expected to be attentive when elderly patients narrate their life stories or experiences. HNs have to treat these patients as their own parents and lift their spirits if they are found low.
- In cases when the HNs have to deal with hefty patients, the employers' families should make sure that either another nurse or a family member of the patient (of the same gender as the patient) is available for assistance.

To guarantee the safety as well as the dignity of the HNs, the agency put forth the following set of instructions to the employers:

- The patient and family should consider the home nurse like a sibling who voluntarily undertook the caregiving task. So, assuring the safety of the nurse is the sole responsibility of the employer.

- Employers are expected to co-operate with and help the nurses to make use of their services effectively.
- Consider the nurse like a family member and arrange all necessary facilities for them.
- Provide a bed, mattress, and chair for the nurse in the same room as the patient.
- Provide necessary protective equipment like gloves and masks when the nurses have to touch the human waste.
- A female family member must be available all the time in cases where female nurses are employed for homebound patients.
- Female nurses should be provided with the instructions for caregiving by the female family members of the patient.
- Food for the nurse must be served on the dining table.
- Ensure that no men (except the patient) are allowed in the room where the nurse stays at night.
- The nurse must not be engaged in household chores, asked to wash other family members' clothes, or do tasks unrelated to the patient's care.
- Cooking for the patient is not the duty of the nurse.
- Ensure that the nurse gets at least 6 hours of sleep a day.
- Employers should not permit any visitors to meet the home nurses without seeking the agency's permission.
- If the patient gets hospitalised, the employer can continue the service after informing the essential details (such as the hospital's name, address, phone number or patient's room number.) to the agency.

3.17 Terms and Conditions About Salary

- The salary of female nurses (within Kerala) is 13,000 rupees and 15,000 rupees (outside Kerala).
- Male nurses have to be paid 15,000 rupees and 17,000 rupees for working within and outside Kerala, respectively.
- Female nurses employed to take care of male patients should be paid on par with men who do the same job.
- Payments should be made in cash. Cheque or Demand Draft payments are not accepted.
- A month's service means 28 days of work and a salary for the same. If the caregiver wishes, they can take two or three days of leave. If they do not use this option, the entire month's salary should be paid.
- The salary of the nurses gets revised from time to time. The monthly salary payments have to be made directly to the employees. Patients or their relatives need not contact the agency office for the same.

3.18 Conditions About the Duration of Service

- A nurse is not encouraged to work for more than three months for an employer.
- If service is required further, the customers can contact the agency, and then a different home nurse will be assigned. In such cases, the employers should inform the agency at least five days before the contract ends. Employers have to bear the travel expenses of both the home nurses in such situations.

- Customers should renew the registration after three months by paying the fees of Rs 2000. If the service needs to be availed further, the registration fees have to be paid for every three months of service.
- When the contract with an HN ceases, the employers are expected to pay the nurses the salary up to the last day of employment besides their travel fare.
- When the nurse finds it difficult to perform their duties properly (whatever the reason be), the agency has the right to mandate the HN to leave the contract.
- If the customers are not satisfied with the services of the nurse, they can request the agency to allot another care provider.
- The agency has the sole right to demand an employer to end the work contract with the nurse they have employed at that time.

3.19 Rules for Home Nurses/ Employees

- The nurses should not interact closely with the patient's family members, relatives, or neighbours. Neither are they encouraged to share any information about the patient's family with outsiders.
- Considering the caregiver's safety, they should be allowed to use the washroom attached to the patient's room.
- If the patient's condition is not critical, do not allow male family members inside the room during the night. Make sure to close the room before going to sleep.
- Nurses should remember not to cause any disturbance to the patient and family with the excessive use of mobile phones.

- Nurses should not perform household tasks at any cost. Nurses should wash the patient's clothes but not perform any other task unrelated to the patient's care.
- Nurses must co-operate with the employers and see that they complete the contract period.
- If the nurse cannot continue working for an employer (regardless of the reason), they must inform the agency office in advance.

The agency also warns that disciplinary action will be taken against those nurses who violate its norms and rules. It adds that the district court will deal with any nurse accused of a case.

The Indian Red Cross Society's *Kottayam* branch has several instructions like those given above. However, its staff is advised to properly understand a patient and family before signing the contract with them. They are also directed to contact the office if they experience any kind of mental or physical harassment from the client. As per the guidelines, if the HNs do not complete the duration and end a contract before it should (for reasons that are not genuine), they are bound to pay the compensation. In addition to some of the rules for customers quoted above, this organisation clarifies the following points:

- The clients are expected to share all the required information about the patient and family and reach a consensus before signing the contract with a home nurse.
- The clients should not harass the home nurse mentally or physically. Neither should the patient or family misbehave with the nurse.
- The monthly salary for male nurses who work within Kerala is 16000 rupees, and it is 15000 rupees for females. The monthly salary for men who work outside Kerala is 17000 rupees and 16000 for women. Female nurses who take care of male patients should be paid the same salary as male nurses.

The Indian Red Cross Society's branch located at *Pathanamthitta* district was also a part of the study. It has an instructions booklet (Plate 3.3 shows its cover page) with similar information. As per the guidelines, the home nurses should wear the Red Cross Badge throughout the day at work. The staff is also instructed to wear a white uniform during their duty hours. Somehow, this practice is not being followed in recent times as it could be known from some of the HNs from the organisation who participated in the study. The office staff at the society's branch opines that wearing the uniforms gives the employees a more professional look and dignity than the staff sent by other private agencies. They feel that the employees should not be treated as servants but as professionals sent by a reputed organisation like the Red Cross Society. The nurses' attire is seen as supportive in a way since it helps build a professional image.

An agency situated at *Kottayam* district instructs its employees to behave well with the clients, not let the elderly patients become over-dependent on the caregiver, not to use mobile phones when on duty, and not to encourage the HNs' relatives to visit their workplaces (client's home) without informing the same at the agency office. The male HNs are warned to avoid smoking and/or alcohol consumption during their duty hours. The instructions for customers highlight that the maximum duration of the contract with a particular HN is six months. If the services are to be continued, they have to contact the agency and hire another worker. The agency also states that it will not assign more than three employees during a period of six months.

Another agency in the same district instructs the HNs not to use telephone, television, or other electronic appliances at the client's home without their permission. Neither are the employees supposed to enter any bedrooms or open almirahs in the client's house. Like some other agencies, this also warns its employees with this statement "If you are accused of any theft or other issues during your stay at the client's home, the responsibility of proving your innocence lies with

you”. It is added that the clients have the right to check the HNs’ baggage when they leave their workplaces at the end of the contract.

In its instructions for clients, an agency from the *Thiruvananthapuram* district asks them not to get into a direct contract with the nurse or allow them to work for their relatives/ neighbours without informing the agency. This implies the agency’s concern that their mediator role will cease. The clients are also asked to provide proper medical care to the nurse if they fall sick. The agency also appeals to its clients to try their best not to create legal issues if they have a problem with the nurse. They are requested to consult the agency director to reach a consensus and solve the problem.

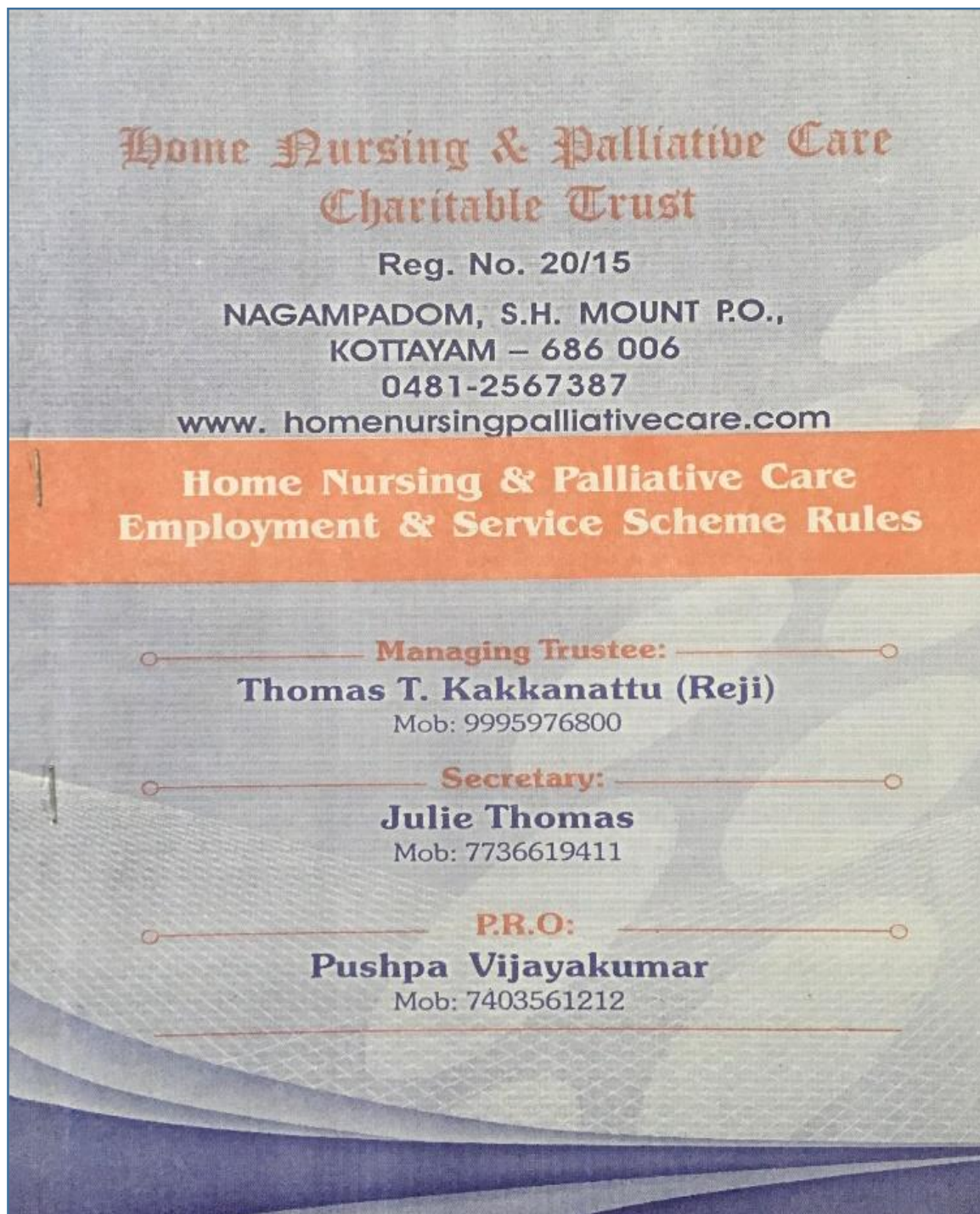
An agency from the Kollam district clearly instructs the clients that a home nurse should not be made to work for more than 8 hours a day. A few other agencies have also emphasised that the caregiver should be provided with enough rest and time to sleep. The agency’s guidelines to the staff state that the nurse should contact the agency and make calls to the office at least once a week.

In its guidelines, one of the agencies from the *Thiruvananthapuram* district mentions that the HNs can accept money or any other gifts given voluntarily by the clients, but they should not ask for it. The HNs are also discouraged from borrowing money from their clients. The clients are cautioned that the money and other valuables kept at their homes are their sole responsibility. If the clients lose any such valuable item and find that the home nurse has stolen it, they can file a complaint to take appropriate legal action against them. The agency declares that it will not be responsible for the theft in such an instance. This agency’s stand is different from several others who urge the clients to contact the agency and try to resolve the issue.

An agency from *Ernakulam* district guides its customers to:

- Provide nurses with protective equipment and sanitary substances like gloves, masks, cotton, bandage, and anti-septic lotion.
- Ensure that the HN gets proper food and rest on time. If the nurse has to stay awake at night for the patient's care, they should sleep during the daytime.
- Allow the HNs to make calls to the agency at any time of the day. However, other calls should be restricted. Without the agency's permission, the HN should not be allowed to make any outside visits.
- Not persuade the HN to break the ties with the agency or employ them without the agency's knowledge.

Plate 3.2: Cover page of the instruction booklet of an agency from the *Kottayam* district



Source: Fieldwork

Plate 3.3: Cover page of the instruction booklet of Red Cross Society branch
Adoor, Pathanamthitta district

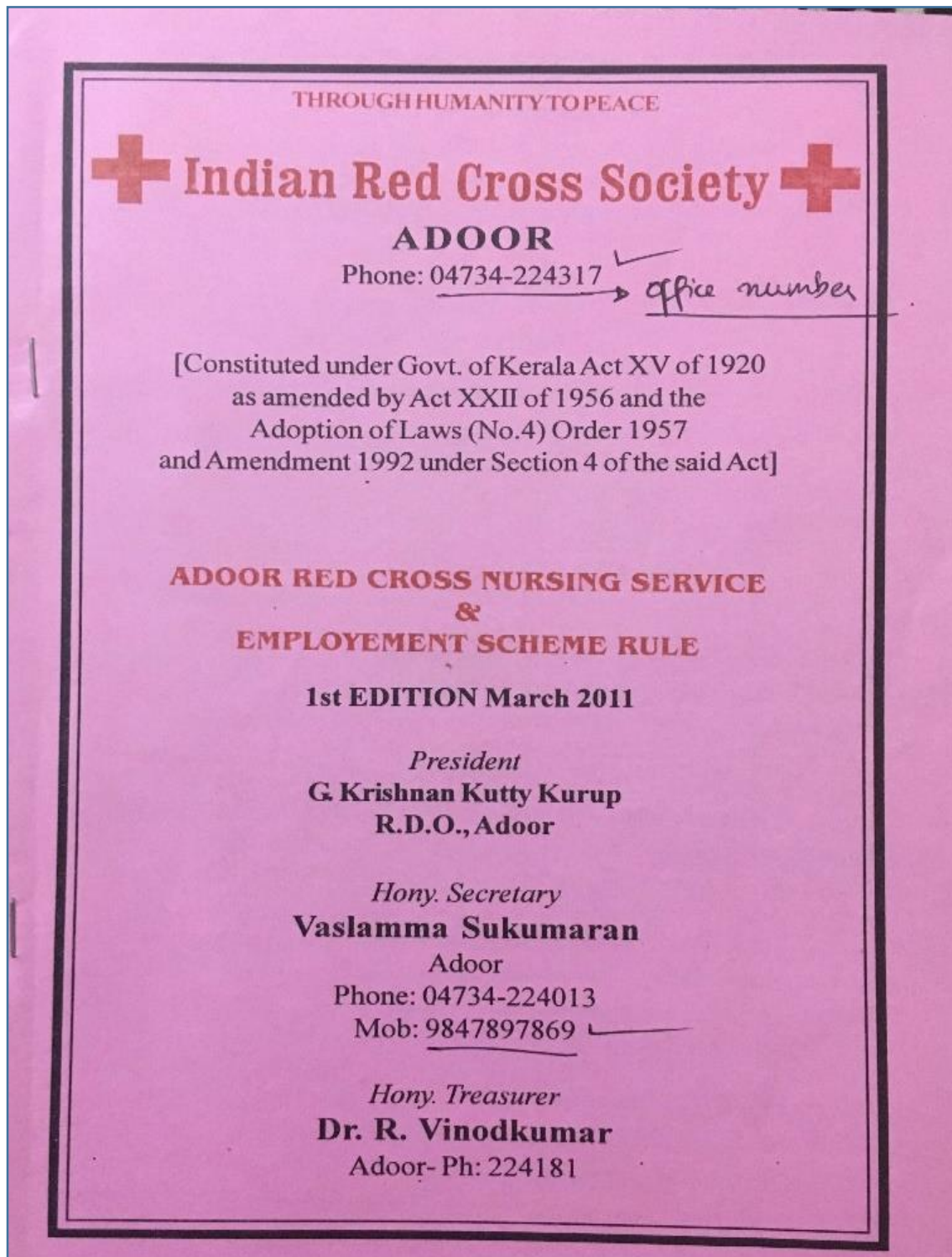


Plate 3.4: A sample of the instructions given by an agency to its customers

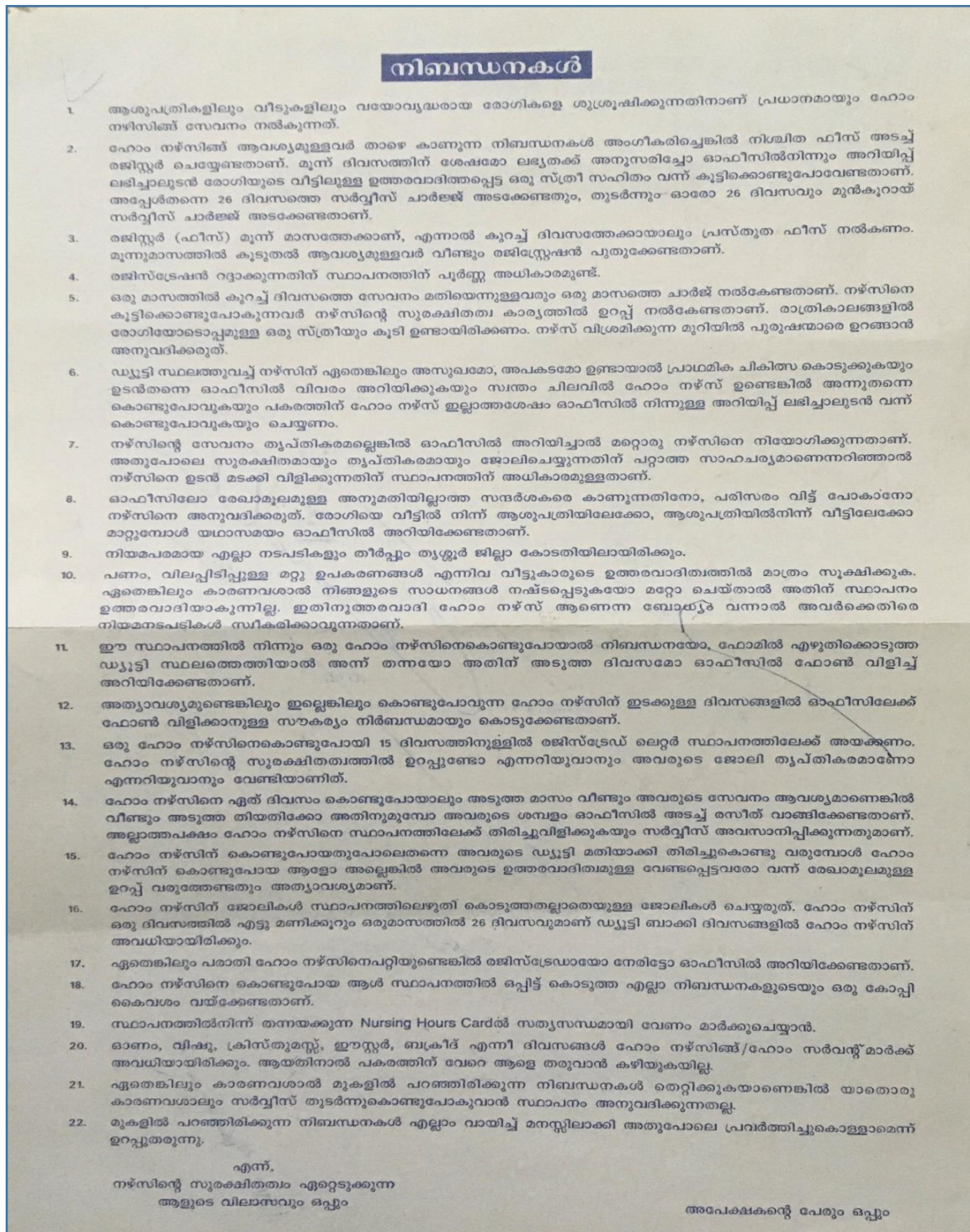


Plate 3.5: A sample agreement form to be filled by the customers



Diya Home Nursing

Near GHS, Attingal, Thiruvananthapuram - 695101
Ph: 9496173028, 8281302876, 9496023025
Reg.No. 015

APPLICATION FOR NURSING SERVICE

1. Name of Applicant :
അപേക്ഷകന്റെ പേര്
2. Address :
വിലാസം
3. Phone No Residence , Mobile :
ഫോൺ നമ്പർ
4. Address of Patient with Telephone No. :
രോഗിയുടെ വിലാസം ഫോൺ നമ്പർ സഹിതം
5. Whether the Patient is at Home or Hospital :
രോഗി വീട്ടിലോ അഥവാ ആശുപത്രിയിലോ
6. If in Hospital give particulars :
ആശുപത്രിയാണെങ്കിൽ വിശദവിവരം
7. Mention the Sex and Age of Patient :
രോഗി സ്ത്രീയോ, പുരുഷനോ എന്നും, വയസ്സും
8. State the approximate period of service required and about what time :
സേവനം എത്ര കാലത്തേക്കാണ്, എപ്പോഴാണ് വേണ്ടത്

DECLARATION

I.....hereby declare that the particulars furnished above are true to the best of my knowledge and belief, fully agree with the terms and conditions

ഞാൻ മുകളിൽ പ്രസ്താവിച്ചിരിക്കുന്ന എല്ലാ വിവരങ്ങളും സത്യസന്ധമാണ്, നിബന്ധനകൾ പൂർണ്ണമായും അംഗീകരിക്കുന്നു.

സ്ഥലം

തീയതി

Signature of Applicant

അപേക്ഷകന്റെ ഒപ്പ്

മറുപുറം (P.T.O)

3.20 Perceptions about Caregiving and Caregivers

To understand their perceptions about the nature of work performed by their staff, the informants' ideas of 'caregiving' and 'a good caregiver' were examined. For all the respondents, caregiving meant supporting the patient in their day-to-day activities and fulfilling their healthcare requirements. This did not mean that a person who lacks knowledge about healthcare tasks is a bad caregiver. Nineteen agency owners expressed that assisting the patients with their personal care needs and providing them with companionship is their primary expectation of a caregiver's role. They added that a caregiver must ensure that the patients do not feel isolated or bored. For this reason, they state that any able-bodied and able-minded person can be a caregiver. Only four respondents considered that their nursing qualifications and educational status make people better caregivers.

While explaining their notion of an ideal caregiver, all the respondents mentioned qualities such as diligence, commitment, patience, honesty, cleanliness, and the ability to get along with the client's temperament. The four agency owners mentioned above added the educational qualification of the caregiver to the list of desirable qualities. Regarding gender-specific characteristics, a preference for married and middle-aged female caregivers was observed. All the agencies that hire male caregivers wanted them to be teetotalers. These preferences indicate that the caregivers' personal qualities and habits and the maintenance of etiquette are the most valued aspects. Every respondent mentioned that a good caregiver should perform the tasks assigned to them without any kind of hesitation or abomination. By this, they meant the tasks like bathing, toileting the patients, or dealing with the patients' excrement. A couple of respondents pointed out the difficulty some of their staff initially had with these tasks, which they later got used to.

All the agency managers agree that the primary duty of the caregivers is to look after the patients. However, almost all the agencies (except the Red Cross Society and a few others) allow the caregivers to involve in the clients' household chores based on the requirement. The caregivers are required to perform additional duties for an extra payment. Otherwise, they must report it to the agency owners if the clients make them carry out tasks that are not a part of the formally agreed list of duties.

The respondents' opinions about their staff being labelled as 'home nurse' was explored. More than half of them believed that the term is appropriate for the caregivers since it truly translates the type of work they perform and conveys the essence of the job. They added that a greater part of their workforce is sincerely striving to improve the health and lives of the patient they care for. The label acts as a kind of recognition for the good work they perform, and it lifts their morale. While four respondents believed that only nursing qualified people deserve to be called home nurses, two others stated that the label is apt for those employees who are willing to acquire the requisite knowledge about nursing activities. According to the agency owners, the tag of a 'home nurse' seems to have bestowed more dignity to the caregivers when compared to other terms like helper or maid. However, they warn that a label alone cannot change the mistreatment by some clients or certain misperceptions about these caregivers by the general public.

Case - 01

Snehatheeram, literally meaning shore of love, is a home nursing agency established in 2000. Its managing director, George Xavier, informed that the institution has three other branches, and the main branch is located in the Thiruvananthapuram district. Along with the home nursing

agency, Xavier runs an elderly care home. Their main office has more than 200 home nurses registered and working for them. When asked about the rationale behind starting the home care agency, Xavier stated that it was his long-standing wish to deliver caregiving services to patients in need.

The agency provides a week of training on healthcare tasks to its employees. The training classes are conducted by final year nursing students from a reputed institution in the district. The agency owner's satisfaction with the agency's staff was queried. To him, satisfaction depends on the nature of the workers. While some are very well-behaved with the clients and families, a few others do not have any kind of commitment to the job. Xavier recollects a few caregivers involved in instances of theft and quarrelling with the clients. He points out that such cases are troublesome due to police and court interference.

The salary paid to the female caregivers varies from 12,000 to 15,000 rupees, while the women involved in postnatal care earn more than 20,000 rupees for a month's work. Men are paid between 15,000 and 17,500 rupees, which is approximately 2,500 rupees more than their female counterparts who undertake contracts other than pregnancy care. As per the agency owner, the differential payment is influenced by the patient's gender. He voices that, unlike several other agency owners, he pays the same amount to female caregivers who take care of male patients. He does not want to discriminate against female HNs who are ready to serve patients regardless of their gender.

Xavier mentions that the agency provides a home nurse for a particular client for a maximum of one year. Post this period, if the client requires the services of a caregiver, a different person will be assigned the duty. He informs that more than half of the agency's clients need employees to help them with household tasks and the patient's care. In his view, the cleanliness and personal hygiene of the caregiver are the most sought-after characteristics as several customers enquire about these traits before hiring an employee. He thinks that the caregiver's personal qualities matter more than their educational qualifications since any person who has the interest and physical abilities to look after patients can undertake the job of a care provider.

He remarks that the home nursing industry has a lot of scope in the present scenario since it requires formal caregivers to cater to the needs of nuclear families with ailing members. He adds that his agency, being one of the oldest in the district, is trusted by several customers. However, the competition in the field has been increasing as several new agencies have opened up in different parts of the district. He is content that many patients receive support and assistance from the caregivers who work for his institution. Though his business has been doing considerably well, the satisfaction of generating jobs for many unemployed women and his connections in the industry- with their employees, clients, and other agency owners- contribute to his happiness.

Case - 02

Karunya home care, established in 2008, is a home nursing in the Kollam district. Karunya translates to compassion. Sheela, the owner of the agency, is a widow. She has a few years of experience working as a home nurse for one of the largest home nursing agencies in the district. She started this agency as a source of income, but she has been interested in serving the ailing. As

she single-handedly manages the agency office, there are only close to fifty home nurses. The agency also provides house maids for customers who require the service. Sheela remarks smilingly, “the greater the number of employees, the bigger the headache”. However, she has been happy with the agency’s services to its clients. Though the agency has not been doing really well as a business, she finds contentment in becoming a catalyst that has brought a change in the lives of several patients.

Sheela informs that most of the agency’s clients belonged to middle-class or economically well-off families from the state’s three major religious communities. They are settled in Kollam and its nearby districts. Sheela cited that several clients do not care about the employee’s religious affiliation, while some Hindu and Christian clients mention that they do not want a Muslim person. She added that this could be due to their perception that Muslims have a culture different from theirs and are difficult to adjust to. She added that the factors that decide the clients’ decision to hire a particular employee are their educational status and physical fitness. Besides this, the agency will be enquired about the caregiver’s records to understand their patience level and empathetic nature. Sheela reports that the agency does not have any rules regarding the duration of a contract. An employee would be allowed to work for a particular client as long as the client wants the services to be continued.

The agency’s recruitment procedure of the caregivers reveals that anyone with a healthy body and mindset to work would be given employment, provided they do not have any criminal background. The educational qualification of the employee is not a criterion as their work mainly does not require any formal or specialised education. The caregivers’ services typically assist the patients’ daily activities. Home nurses are given training by the agency yearly once to perform the healthcare tasks. This one-day class is taken by a senior nurse who works at a government hospital.

Apart from this, Sheela provides the details of the clients and instructs each employee on the etiquette to be followed with the client and family once they undertake the contract. It was informed that most of the employees registered with the agency have continued for a more extended period. While some continued for months, the majority has worked for years. Sheela mentions that a couple of employees have been with her for almost a decade.

The salaries paid to the female caregivers range between 12,000 and 15,000 rupees, barring the postnatal care specialists who are paid not less than 18,000 rupees for a month. The male caregivers earn between 15,000 and 18,000 rupees. Sheela notes that the disparity in payment is influenced by the patients' gender as well as the type of illness suffered by them. Referring to the paucity of male caregivers in the sector, she states that the agency has only four male employees. For this reason, she has to allot female caregivers for male patients at times. However, these women do not get paid on par with their male counterparts. She explains that male caregivers demand more payment for staying at the client's home while the women adjust better to the situation and do not complain about the salary.

Though this differential pay exists, Sheela has been considerate with her staff who needed financial help. While interviewing one of the caregivers who works for the agency, the researcher was informed that Sheela lent her 5,000 rupees when she wanted some money for her daughter's educational expenses. However, she did not accept the money when the caregiver tried to return it. Yet another case is that of a caregiver who was in a difficult situation when her husband was hospitalised in a critical condition. Sheela then requested all the employees to pool some money, contributed the rest of the amount, and gave the woman a sum of rupees 10,000. This information was cross-checked with Sheela. These instances manifest that more than running a business, the agency owner is empathetic towards the well-being of her staff as she takes the initiative to help

them in difficult situations. Being a widow, Sheela states that she understands how important it is for widows, divorcees, and unmarried women to be financially independent. For this reason, she takes pride in offering jobs to women who needed them to keep their lives going.

3.21 Discussion

This chapter looked at the cases of 24 home care agencies in the study area. The agency owners' reasons to start a business in the home care sector, the details about their staff and clientele, the process of selection and recruitment of their staff, the training provided to these staff, and how the agency owners manage their business have been explained. All the home care agencies in the sample provide around-the-clock services to their clients, while some also offer part-time services as per the clients' requirements. In their advertisements, some of the agencies emphasise that their home nurses take complete care of the patient and share the responsibility of the patient's kin. Most agencies reported making their services available to clients in other districts, and Malayali families settled in other states. However, international migration did not happen in any cases, and the agencies did not encourage their staff to work abroad. Most of the agency owners believe that the services of home nurses have become inevitable, especially for the care of the elderly belonging to families where all adult members are involved in paid employment or in cases where the family members do not reside with the ailing elderly. This fact casts light on the declining role of families in providing hands-on care to their relatives. Caregiving, which was considered one of the functions of a family, has been transforming into a contractual arrangement. Like any other service sector industry, home nursing agencies also provide their services based on the requirements and demands of their customers.

The reasons for starting the venture reveal that nearly half of the agency owners have been influenced by greater missions than the profit motive. These agency managers have cited creating jobs for the unemployed (particularly for unemployed women) and providing care for the ailing whose kin are unavailable as the major aims behind establishing the business. The two case studies presented in the chapter testify the satisfaction they derive by fulfilling this mission. Socci, Clarke, & Principi (2020) believe that social entrepreneurship is “a means to alleviate social problems and catalyse social transformation” (p.2). Though social entrepreneurship is often thought of as a not-for-profit business, several scholars opine that “ventures created by social entrepreneurs can certainly generate income, and they can be organised as either not-for-profits or for-profits” (Martin & Osberg, 2007, pp. 34–35). In that way, some agency owners who prioritise philanthropic motives and focus on creating social value with their services can be considered social entrepreneurs. Peredo & McLean (2006) argue that “social entrepreneurs contribute to the welfare or well-being in a given human community” (p.59). The authors also support the view that “wealth is just a means to an end for social entrepreneurs” (p.59).

The information on the backgrounds of the caregivers confirm that most of them belonged to economically backward families and had personal issues like financial difficulties, death of life partners, abuse of alcoholic spouses, or chronic illnesses of family members that encouraged them to choose the work. Only a handful of employees seemed to have taken up the job for altruistic motives, showing genuine interest to serve patients. George (2013) also mentions similar reasons for the entry of workers into caregiving. Though most of the caregivers who took part in the present study reported having the support of their families, it was noticed that some of the female caregivers involve in the work despite the disagreement of their kin owing to several reasons including, the suspicious nature of a live-in caregiver’s job. It was found that some of the

caregivers do not reveal the details of the work to their relatives and friends. Similarly, they hide their personal details, such as caste affiliation, from their clients, which was discussed in the previous chapter in detail. It was identified that some of the agency office staff also are hesitant to disclose their occupational identities. One such case has been presented in the findings above. Instances like these throw light on the stigma attached to caregiving jobs and the negative perception that prevails about the caregivers in Indian society. The lower caste employees' fear of being ill-treated by the upper caste employers reflects the caste discrimination prevalent in the country.

When it comes to the gender pay gap in the industry, some of the agencies were not paying their female employees at par with their male counterparts. Despite this wage disparity, most agency owners refuse to admit that gender inequality exists in the industry. The details about the differences in salaries of both genders are presented in the findings. This explains the mismatch between what the respondents claim and what happens in reality. The agency owners who promote the differential pay justify their stand by indicating that male caregivers are scarce in the profession, and to retain them, they need to be paid on par with other male workers who are daily wage earners. The majority of the respondents believe that men deserve a higher payment since they are generally paid more than women in other jobs. A few others mentioned that looking after male patients was a difficult task. Male caregivers demanding more payment was reported by most of the respondents. A study of home-based caregivers in Kerala by George (2013) also notes male employees getting paid better wages. This trend of unequal pay for equal work established in the home nursing industry in Kerala calls attention to the gender inequality at the workplace that is observed across industries and professions in the country.

The agency owners reported that the factors that have a say on the client's decision to hire a particular caregiver include characteristics such as physical fitness, patience level, honesty, cleanliness, personal hygiene, educational qualification, and interest in caregiving. George's (2013) study of an organisation named Self Employed Women's Association (SEWA) in Kerala throws light on professionalising domestic workers by focusing on their training on aspects like "knowledge of the job; punctuality at work; good personal hygiene; using a uniform; respecting the privacy of the home; and being honest and diligent in one's work" (p.72). However, the present study finds that, barring a few organisations like the Red Cross Society, the educational qualification of the staff is not a selection criterion for the majority of the private nursing agencies. The interest in carrying out caregiving tasks and physical strength seemed to be more important qualities that a caregiver requires than educational standards. Some agency owners used this argument to substantiate the point that most of their clients require the care providers' assistance with personal care tasks and not medically oriented needs. Providing emotional support to the patients was cited as one of the main tasks performed by the caregivers despite the truth that it often goes unnoticed by the clients or society. However, some owners do not forget to acknowledge that being equipped with healthcare tasks improves the respectability and social standing of the home nurses.

Even though they realise the significance of offering healthcare training to the home nurses, more than half of the sample does not provide their staff with adequate training. In her study of SEWA, George (2013) finds the organisation imparting "theoretical inputs and practical training to their staff with the help of professional nurses" (p.72). The right ways to perform tasks and techniques such as "patient diets, sponge bath, massage, exercise, administering the bedpan, individual hygiene" were taught to them (George, 2013, p.72). The present study recognises the

need to conduct intensive training programs to enable the home nurses to perform all kinds of nursing tasks efficiently since most of the staff lack basic nursing knowledge. A study by Chichin and Cantor (1992) also noted the need for “regular, ongoing, in-service training” for workers involved in home care. Some of the care workers who took part in their study “expressed a desire for more knowledge about dealing with older people and their disease entities, and also for more technical training” (Chichin and Cantor, 1992, p.101). The authors argue that though these caregivers are often hired to take care of “basic domestic and personal care assistance, the need for in-service training in a variety of areas will be even more necessary as high technology becomes more commonplace in the home” (Chichin and Cantor, 1992, p.101).

In a study by National Research Council (2011), the factors that hinder the retention of care workers in America include the “perceptions of lack of respect, lack of control over the workplace, and limited opportunities for professional growth that contribute to low job satisfaction” (p.48). As cited by the informants in the present study, the reasons for the employees quitting their jobs include difficult work conditions at the clients’ homes, lack of freedom, isolation from family members and coworkers, getting better job opportunities, ill health that restricts performing arduous physical tasks. Nonetheless, disappointment with the salary was not mentioned as the reason by any of the respondents. Neither were the home nurses concerned about career growth since it is a job in an unorganised sector that does not offer any scope for professional advancement. Research by Chichin and Cantor (1992) found that despite the perception that the home care industry has low retention rates, “job turnover was lesser than anticipated and that there was a group of steady employees with relatively long tenure both in the industry and with one particular agency” (Chichin and Cantor, 1992, p.94). The present study also found reports of staff who have been continuing with their agencies for years and some employees who have been

working since the agencies' inception. However, it is envisaged that providing the caregivers with better training on healthcare tasks and decent employee benefits would attract and retain good workers in the industry and pave the way for enhancing the respectability and worth of the profession.

As far as the agency's role in regulating relationships between the clients and employees is concerned, it was identified that each agency has a set of rules that both parties involved in a contract have to adhere to. The agencies chart a care plan for each customer, and the home nurses are supposed to work accordingly. If clients want to hire a caregiver to attend to any household tasks, they must pay an additional fee. To ensure compliance with the norms, several agencies clearly instruct the care providers to not engage in household chores, wash other family members' clothes, or do any task unrelated to the patient's care. At times, cooking for the patient is also not considered the nurse's duty. The staff is asked to bring it to the agency's notice if they face any difficulty at a client's place or the client/ family tries to take advantage of their services. Before an employee undertakes a contract, the agency instructs them on the etiquette to be followed with the client and family. Several agencies advised their staff not to over-involve in the clients' family matters, while some warned them to make sure the elderly patients do not become over-dependent. Similarly, a study from Canada by Aronson and Neysmith (1996) observed the "home care organisations cautioning their workers against over-involvement with clients" (p.62). Research by Mears & Watson (2015) reveals that the care workers were "encouraged to form good relationships and respect the wishes of the older person, but not to "allow" the older person to become too dependent on these relationships" (p.153). The norms and guidelines put forth by the agencies to regulate their staff and clients throw light on their efforts to function smoothly and sustain in the field with a good reputation.

The next chapter discusses the case of individuals and families who purchase home nursing services.

Chapter 4

When Care Gets Commodified: Analysing The Perspective of Service Receivers

4.1 Introduction

This chapter discusses the cases of individuals and families who are the receivers of services provided by the private home nursing industry in the study area. The socio-demographic profiles of these care receivers and the details of their caregivers have been explored. Their process of hiring the caregivers and the criteria employed in selecting them have been analysed. The reasons for availing home care as explained by the service receivers, their satisfaction with the services and the perceptions of an ideal caregiver are included. The chapter aims to identify the care receivers' remarks about the domiciliary care industry in general and the caregivers in particular. An attempt has been made to unearth whether the participants believe nuclear families have boosted Kerala's private home care industry.

The conceptual definitions of some of the terms used in this chapter require an explanation. Throughout the chapters, the service recipients are referred to as 'clients', 'customers', 'care receivers', 'care recipients' or 'employers'. In this particular chapter, they are also referred to by the terms 'respondents' and 'informants'. The initial criterion of inclusion of the participants was that the informal caregivers of the patients had to be primarily co-residing with them. This criterion was later expanded to include the patients' non-co-residing family members who live in proximity and maintain constant contact with the patients. Though the patients are the actual clients, the clients' families are also included in the category. As most of the patients could not be interviewed

due to their illness conditions or inability to speak, their family members (the primary caregivers or their spouses) took part in the study.

The findings presented in this chapter are based on a sample of 76 home care clients that belong to different parts of the study area. The sample includes people currently availing the home nursing services and a few who used the services earlier. The latter comprises clients who purchased the services not more than five years back. In some cases, the details of the clients were provided by the agency owners. However, a greater number of respondents were approached and recruited for the study by employing the snowball technique.

4.2 Socio-demographic Profile of the Care Recipients

The sample consisted of 60 female and 16 male respondents. Close to one-third of them were aged less than 50 years. The majority belongs to the age category of 51-60 years. All respondents but one were aged below 70 years. Among the respondents, only 12 were the direct receivers of the care services. More than half of the sample was the elderly patients' adult children and spouses. In the remaining cases, either a grandchild, a parent, a sibling, a spouse, or some other relative spoke on the patient's behalf. Almost all the respondents who are the indirect service receivers co-resided with the patients. The remaining few stayed in homes that were in the vicinity of the care recipients' residences. One of the respondents works abroad, and his family resides with the patient in their hometown in Kerala. Out of the 16 male informants, only one was a primary caregiver. Before the arrival of the home nurse, the spouse was singlehandedly taking care of his wife suffering from a mental illness. All the female interviewees were the primary caregivers

for their ailing relatives. Analysing the relationships between the primary carers and the patients revealed that daughters and daughters-in-law accounted for the most carers.

With regard to the respondents' work statuses, 42 were found to be employed, while 13 were retired employees. About a quarter of the informants were not involved in any paid employment. When their employment statuses were analysed by gender, more than one-third of the female respondents were government employees. Nine each were employed in the private sector and retired from service. The remaining were homemakers and, thus, not formally employed. Among the male informants, five were employed in the government sector and six in private companies. While there were four retired government employees, only one person was unemployed. This shows that most of the respondents are/ were involved in some sort of paid employment. The annual income or financial statuses of the clients have not been explored. Since most of them have monthly earnings or pensions, it was expected that they were capable of hiring these nursing services for themselves or their ailing relatives.

The religious and caste compositions of the sample reveal that more than 70% of the clients are Hindus. Among the Hindu clients, 21 were upper-caste people of the Nair community, and the remaining 33 belonged to Ezhava, a community that belongs to the Backward Castes category. The numerical dominance of Hindus in the study area, and Ezhavas being one of the dominant castes in the state is probably the reason for this. None of the clients belonged to Scheduled Castes or Scheduled Tribes. Christian and Muslim clients numbered fifteen and seven, respectively.

When it comes to the gender composition of the patients, more than three-fourths were female. There were only 18 male patients. In terms of age, the majority of the clients are aged above 50 years. To be specific, 54 patients are aged above 70 years. The average age of the patients is 70 years ($S.D = 19.98$). There were ten care recipients aged below 40 years, of which eight

availed the services of postnatal care providers. The greater number of female clients in general and elderly female clients, in particular, can be attributed to two reasons. Firstly, in the study area, women typically play the roles of primary caregivers for their ailing kin. When their male relatives suffer from diseases, women take care of them as much as possible. The probability of using formal caregiving services is lesser in this case. On the other hand, when a woman suffers from an illness, the chances are lesser that her spouse or children will take the responsibility to become the primary caregiver, especially if theirs is a nuclear family. Secondly, women are expected to live longer than men but suffer from several illnesses. The fact that women have higher life expectancy but not necessarily healthier lives has been widely reported by studies undertaken across the country. Older widowed women are more likely to co-reside with adult children that otherwise have nuclear families. Formal employment of these adult children and their spouses is expected to increase the likelihood of hiring in-home caregivers to render care to these ailing elderly mothers.

The age distribution of the patients reveals that the majority are elderly. It could be known that 21 clients had problems related to their increasing age, such as mobility issues, injuries caused by falls, memory loss, or bodily weaknesses, thus requiring assistance with almost all daily life activities. While 16 patients required post-surgery care, eight others were paralysed. A quarter of the patients had cancer, cardiovascular diseases, diabetes, and other lifestyle diseases. Two patients had mental health problems, and the remaining two did not have any severe illnesses but required the support of a care provider. All the patients were reported to be suffering from diseases that are non-communicable (NCDs).

Some of the clients have been using the home nursing services for a few years, while the others used it for a few months. Almost half of the clients reported employing a care provider for less than six months. While one-third of the patients availed the services for more than a year, only

five had home nurses for more than five years. Out of these five patients who hired care providers for an extended period, three suffered a stroke and were paralysed. Irrespective of the total period they hired home nursing services for, some clients have had many care providers work for them. There could be several reasons for this, including the agency cancelling the contract after a particular period, the employer being unhappy with the care provider, or the care provider finding it challenging to adjust with the client's family. More than a quarter of the sample had a single care provider throughout the contract period, among which the majority used the services for three months or less. Seven clients had more than ten people work for them, one after the other. Among these seven, five clients have availed the services for more than five years. More than three-fourths of the sample had employed up to five HNs. The client with the highest number of caregivers used the services for about seven years. They had employed around 55 caregivers in total. As cited by them, the major reasons for availing the services of multiple caregivers are compatibility issues due to the unwelcome nature of the caregiver and the bitter relationship between the patient and caregiver. Some reasons for the same could have been the nursing agency's rule of replacing the existing caregiver with a new employee after a specific period, withdrawal of the contract due to personal reasons and dissatisfaction with the caregiver's work. A couple of clients reported instances of caregivers who went to their homes for a two-day leave but never returned. In such cases, these clients had immediately contacted the nursing agencies and were allotted replacement employees without any delay. A Pearson correlation was conducted to find any connection between the duration of the contracts and the number of HNs hired by a client. The two variables were found to have a moderate positive correlation ($r=0.428$). The test results have been presented in the table below.

Table 4.1: Correlation between duration of services and number of caregivers hired

Correlations		Duration of the contract	Total number of HNs
Duration of the contract	Pearson Correlation	1	.428**
	Sig. (2-tailed)		.000
	N	76	76
Total number of HNs	Pearson Correlation	.428**	1
	Sig. (2-tailed)	.000	
	N	76	76

** . Correlation is significant at the 0.01 level (2-tailed).

4.3 The Care Providers: A Brief Profile

The respondents provided the details of the home nurses they hired. Based on this, the gender and age compositions of the caregivers, their caste/ community affiliations, and the nature of work they carried out have been analysed. Out of the 76 care recipients, about 85% were served by female caregivers. The gender of the last caregiver has been considered for male patients who have had caregivers of both genders. It was discussed in the previous chapter on home nursing agencies that some clients favour hiring female caregivers for male patients. Upon analysing the

18 cases of male patients, it was found that 12 have had male caregivers. One of the clients earlier had male caregivers but had to resort to a female care provider due to some difficulties. The six respondents who did not want to have male care providers view that hiring female caregivers is a better option considering the safety of the womenfolk at their homes. Some also perceive that women are better caregivers compared to their male counterparts. Similar reasons were stated by the nursing agencies for the preference of female caregivers.

The age composition of the caregivers demonstrates that the youngest caregiver is aged 23 while the eldest is aged 68. The majority of the caregivers are aged between 41 and 60. This corresponds to the information provided by the nursing agency owners that most of the care receivers prefer middle-aged caregivers to young caregivers. The reasons for the same have been cited in the previous chapter. Similarly, the sample of caregivers also reveals that about half of them are in their fifties. The possible reasons for this age category outnumbering others have been provided in Chapter 3.

Upon analysing the nature of work carried out by the caregivers in terms of the patients' illnesses, the majority seemed to be involved in geriatric care or the care of patients suffering from lifestyle diseases. As previously stated, eight cases of postnatal care were reported. These clients were inquired if they would choose someone who has experience as a traditional birth attendant/ midwife or someone who has attained nursing education like General Nursing and Midwifery (GNM). A preference for the former was found owing to their experience in post-delivery and neonatal care. The clients who availed this service reported that the traditional post-delivery care providers are known for the herbal medicines that they prepare for the new mothers. These medicines have been considered effective in postpartum healing, and there is no guarantee that qualified nurses would be able to do the same.

As far as the caregivers' religious and caste/ community affiliations are concerned, one-third of the clients have exclusively had people from their own communities work for them. Among these, there were six Latin Catholics, five Muslims, nine Hindu Ezhavas, and five Hindu Nairs. The remaining clients had employed persons belonging to communities different from theirs. While almost half of the respondents had a heterogeneous group of caregivers from different communities, eight have had all their caregivers belonging to certain Scheduled Castes.

Table 4.2: Profile of the care receivers (n=76)

Sl. No	Characteristic	Numbers and Percentages (in parentheses)	Mean & SD (where applicable)
1.	Gender of the respondent		
	Female	60 (78.94)	
	Male	16 (21.05)	
2.	Age of the respondent		The average age of respondents = 48.31 S.D = 11.29
	30 or below	8 (10.53)	
	31-40	4 (5.26)	
	41-50	14 (18.42)	
	51-60	37 (48.68)	
	61-70	12 (15.79)	
	71 and above	1 (1.32)	
3.	Respondent's employment status		
	Employed- Government service	28 (36.84)	
	Employed- Private	15 (19.74)	
	Unemployed	20 (26.32)	

	Retired from service	13 (17.11)	
4.	Respondent's relationship with the patient		
	Daughter	20 (26.32)	
	Son	8 (10.53)	
	Daughter-in-law	13 (17.11)	
	Son-in-law	3 (3.95)	
	Self	12 (15.79)	
	Wife	5 (6.58)	
	Husband	4 (5.26)	
	Father/ Mother	4 (5.26)	
	Sister	1 (1.32)	
	Grandchild	5 (6.58)	
	Niece	1 (1.32)	
5.	Gender of the patient		
	Female	58 (76.32)	
	Male	18 (23.68)	
6.	Age of the patient		The average age of patients = 70 S.D = 19.98
	30 or below	7 (9.21)	
	31 to 40	3 (3.95)	
	41 to 50	3 (3.95)	
	51 to 60	5 (6.58)	
	61 to 70	4 (5.26)	
	71 to 80	23 (30.26)	
	81 to 90	29 (38.16)	
	91 and above	2 (2.63)	
7.	Illness of the patient		
	Age-related illness (including falls, memory loss)	21(27.63)	
	Cancer, cardiovascular diseases, pulmonary diseases, etc.	6 (7.89)	

	Diabetes	13 (17.11)	
	Stroke/ Paralysis	8 (10.53)	
	Pregnancy/ post-natal care	8 (10.53)	
	Post-surgical care	16 (20.05)	
	No serious illness, just assistance needed	2 (2.63)	
	Mental health issues	2 (2.63)	
8.	The religion of the care recipient		
	Hindu	54 (71.05)	
	Christian	15 (19.74)	
	Muslim	7 (9.21)	
9.	Caste/ Community of the care recipient		
	Hindu, Nair	21 (27.63)	
	Hindu, Ezhava	33 (43.42)	
	Christian, Latin Catholic	15 (19.74)	
	Muslim	7 (9.21)	
10.	Gender of the caregiver		
	Female	64 (84.21)	
	Male	12 (15.79)	
11.	Age of the caregiver		The average age of caregivers = 51.77 S.D = 8.18
	30 or below	3 (3.95)	
	31 to 40	0 (0)	
	41 to 50	27 (35.53)	
	51 to 60	37 (48.68)	
	61 to 70	9 (11.84)	
	7 and above	0 (0)	
12.	Caste/ community of the caregiver/s		
	All Hindu, Nair	5 (6.58)	
	All Hindu, Ezhava	14 (18.42)	
	All Scheduled Castes	8 (10.53)	
	All Christian, Latin Catholics	8 (10.53)	

	All Muslims	5 (6.58)	
	Multiple HNs from different communities	36 (47.37)	
13.	Community affiliations of the care recipients and their caregivers		
	Both belong to the same caste/ community	25 (32.89)	
	Both belong to different communities	51 (67.11)	
14.	Duration of the caregiver's services		
	One month or less	15 (19.74)	
	About 3 months	12 (15.79)	
	About 6 months	9 (11.84)	
	6 to 12 months	10 (13.16)	
	More than a year	25 (32.89)	
	More than 5 years	5 (6.58)	
15.	Total number of caregivers employed so far		
	Only one	21 (27.63)	
	2 to 5	46 (60.53)	
	6 to 10	2 (2.63)	
	11 to 20	5 (6.58)	
	21 to 30	1 (1.32)	
	31 or above	1 (1.32)	

4.4 Hiring the Caregivers: The Process and Selection Criteria

Almost all the care recipients would have a few expectations, demands, and requirements when they decide to hire a care provider. They convey these requirements to the nursing agencies if they hire someone without a reference. Otherwise, the client would contact the nursing agency and request a particular employee referred by somebody from their social circle who had hired them earlier. Details about the caregivers' work histories are expected to simplify the hiring

process since credible sources provide unbiased opinions on the caregivers' character. While ten clients hired caregivers based on their acquaintances' good reviews and recommendations, the remaining had the caregivers allotted directly by the home nursing agencies. Out of these, all except four were assigned a random care provider. This means that most of the sample hired individuals who were strangers to them. The process of hiring the caregiver has been explained below with the help of a flow chart (Figure 4.1).

The respondents' major requirements, selection criteria, and their opinions on the traits of good caregivers were explored. It was found that about 70% wanted the care provider to look after the patients' needs exclusively. Out of these, six patients had the caregivers attend to their personal care needs and offer companionship. The remaining HNs were hired to assist mainly with the medically oriented needs of the patients. The other 22 clients required some housekeeping support from the caregivers besides their involvement in the patient's direct care. Nonetheless, data revealed that the HNs assisted several clients' families in household chores. In these cases, the HNs volunteered to offer help. While explaining their notion of an ideal caregiver, all the clients reported searching for a person with a caring and considerate attitude. Honesty, reliability, sincerity and commitment to the job are also valued traits. Most respondents believed that the care provider needs to be understanding and tolerant to deal with the patient's emotional state and attend to their requirements. The clients' responses on the caregiver's most valued quality ranged from trustworthiness, patience, and honesty to cleanliness and hygiene. Trustworthiness and the caring nature of the individual were the qualities cited by the most number of clients. While 15 respondents valued patience the most, ten others considered the caregiver's hygiene and cleanliness as the essential trait. It must be noted that only six clients valued the caregiver's knowledge of healthcare tasks as the most desirable quality. These preferences indicate that the

caregivers' personal qualities and habits required to maintain good patient-caregiver relationships are often the most sought-after. (Figure 4.2)

All the clients seemed concerned about the care provider's gender. This does not mean that care providers of the same gender were sought for all the patients. For female patients, it was mandatory to have female care providers. As mentioned above, clients did not always prefer people belonging to the same gender when it comes to the case of male patients. All the respondents except one reported being concerned about the caregiver's age, wanting to hire middle-aged people. Persons aged between 45 and 55 are considered apt as they are generally believed to manage all household affairs properly. Individuals of this age category are also thought to be possessing the abilities and efficiency (കാര്യപ്രാപ്തി or 'Karya Prapthi' in Malayalam) to carry out caregiving tasks. Several respondents pointed out that hiring a person above 60 years of age is risky since they are more likely to suffer from illnesses. Similarly, choosing someone young or below 40 years old comes with other challenges. These include suspicions about the impatience of youngsters to attend to the needs of elderly clients, cases of robbery, complaints about the work environment and facilities, or young women developing unwanted relationships with the clients' male relatives. Acquaintance with the person was considered an important aspect by 12 respondents. These people believed it was better to hire someone known to them or their connections personally. Ten out of the twelve people reported contacting the nursing agencies and requesting to assign the caregiver known to them.

It is worth noting that around three-fourths of the sample were not bothered about the educational qualification of the care provider. They were seen approving the caregivers' experiential knowledge and did not prioritise their formal education. Only eighteen respondents wanted to hire a person educated at least till Class 10th. Some of them liked to have nursing-

qualified employees, but they admitted that such people are hard to find in the job. All the clients were particular about their care providers' health and physical fitness. By fitness, they meant people who are strong enough to handle the patients, lift them and assist in all daily activities. Middle-aged and able-bodied people were preferred by most of the clients. All clients except one seemed to be unconcerned about the caregiver's physical appearance. However, several respondents hinted that though physical appearance or beauty is not a criterion, they like the caregiver to appear neatly groomed and hygienic. The one for whom appearance was a selection criterion wanted the caregiver to be 'clean looking'. As per this client, the looks and how a person maintains their appearance speak a lot about their personality.

It was already heard from the home nurses and the agency owners that several clients prefer people from their own castes to those from other communities. Upon confirming the same with the clients, only ten participants favoured people from the same community. The rest seemed to be okay with people who belonged to any group. However, 16 informants reported avoiding people who belonged to lower castes, Scheduled Castes or Tribes, and Muslim communities. Among them, ten clients had difficulties adjusting with the caregivers, who, according to them, are not culturally compatible. The other six mentioned that Scheduled Castes such as *Kurava* and *Pulaya* are less hygienic, and thus, they would not like to get in contact with such people. It should, however, be noted that though only ten respondents expressed it, 25 were found to have employees that belong to the same castes. Different reasons were given for this similarity in caste backgrounds. While some stated that they got assigned a caregiver from the same caste by coincidence, a few others believed the nursing agency must have purposely allotted someone from the same community. It is assumed that a few respondents may not have revealed the truth about the caste of the caregiver being a selection criterion. One of the informants who belonged to a

higher caste remarked, “We did not want *Pulayas* since we are unsure how clean they will maintain the patient and the surroundings. We may like to hire someone from our community, but we do not easily find people belonging to our caste. So, we often have to settle for anyone ready to work”. This comment reveals that caste is a concern for some clients since they are suspicious of lower castes, particularly those considered ‘less clean’.

An effort was made to identify if the family types and the marital statuses of the care providers matter to the clients. Nineteen of them were found to prefer married people who lead family lives. The rest were okay with employing widowed and divorced persons but somehow did not favour unmarried young women. Since some clients mentioned that they wanted housekeeping support from the care provider, it was decided to find if the culinary skill was a criterion for choosing the caregiver. 17 out of the 22 respondents who wanted housekeeping support stated that they liked the caregiver to cook the kind of food their family members preferred to eat. This was especially the case with families that consumed non-vegetarian food. The rest were not bothered about the employees’ cooking skills since they did not want help in the kitchen. Some of the clients were fine with the care providers carrying out cleaning tasks but disliked taking their help in cooking. All the clients considered the cleanliness of the individual since they favour someone who maintains hygiene and keeps the surroundings clean.

The monthly payments received by the caregivers have already been explored in Chapter 3. Similarly, the previous chapter on nursing agencies also presented the data on the amount taken from the clients and the salaries paid to the caregivers. The monthly payments the care recipients make for the services were analysed to confirm the same. The amounts ranged from 10,000 rupees to about 24,000 rupees. 13 respondents paid the HNs less than 12,000 rupees. This was either because they used part-time services or because the services were used a few years back when the

charges were lesser than the present. More than a quarter reported paying their employees between 14,000 and 16,000 rupees. A similar number paid salaries ranging between 16,000 and 18,000 rupees. Only one of the clients paid a salary above 20,000 rupees, which was for postnatal care. The employers of male caregivers paid them between 14,000 and 18,000 rupees.

To identify the patient's involvement in the decision-making process, it was analysed if the patients' opinions were considered before hiring the care provider. The sample consisted of 12 respondents that purchased the services for themselves, and all of them were involved in the decision making. A little above one-third of the sample informed the patients and sought their consent before employing the caregiver. Though 13 respondents informed the patient about the care provider's arrival just for formality, they did not feel that the patient's approval was necessary. The remaining people did not inform the patients since they were severely ill to respond or their opinions were not considered worthy of seeking.

Here is the case of a family that employed a home nurse around two years ago. The informant explained their requirements and the criteria for selecting the caregiver.

Case - 01

To take care of his 86-year-old mother, Sujith's family hired a caregiver through one of the leading home nursing agencies in their district. Devi, Sujith's wife, was the primary caregiver for the patient who had been suffering from Parkinson's disease. Unfortunately, the patient fell one day. When taken to a hospital, the patient got her leg plastered and was advised bed rest at home. Home care was recommended as the patient was aged, and the doctors did not suggest that the patient undergo surgery. Devi found it hard to manage both work and her mother-in-law's

care. Since Sujith and Devi were working, and their children were students, none of them had enough time for the patient's care. Sujith has two siblings; both settled in outlying districts. They were not ready to look after the ailing mother but agreed to contribute to her medical expenses. These children did not want to admit their mother to an elderly care home since they felt that would spark a debate among their relatives. Despite their busy schedules, they did not want to be blamed for not looking after their parent. It was then that the family decided to use the services of a formal care provider.

They wanted to hire a woman who could be with the patient full-time to constantly monitor her, provide timely food and medicine, and assist her daily activities. They preferred someone aged between 45 and 55, but strong enough to handle the patient. Trustworthiness, commitment to the job, caring attitude, and patience were the qualities they sought in a caregiver. They did not bother about the caregiver's educational qualification or caste affiliation. They wanted the HN to solely look after the patient and not be involved in household chores. They believed that a trustworthy person would take responsibility for the house when the couple went to work. The family was satisfied with the caregiver's services and acknowledged their support in treating the patient affectionately and making the caregiving process easier for Devi.

Table 4.3: Hiring and selection of the HN

Sl. No	Characteristic	Numbers and Percentages (in parentheses)
1.	Mode of hiring the HN	
	Directly through a home nursing agency	66 (86.84)
	Recommended by someone on social network	10 (13.16)
2.	The primary requirement of the client	
	A caring person to look after the patient	54 (71.05)
	Someone to provide Patient care and housekeeping support	22 (28.95)
3.	Selection of the HN	
	Randomly chose one HN from the agency	4 (5.26)
	Allotted one by the agency	62 (81.58)
	Asked for a particular HN since there was some acquaintance	10 (13.16)
4.	Salary of the HN	
	10000-12000	13 (17.11)
	12000-14000	11 (14.47)
	14000-16000	21 (27.63)
	16000-18000	21 (27.63)
	18000-20000	9 (11.84)
	Above 20000	1 (1.32)
5.	Patient informed before employing the HN	
	Yes, since it was necessary	39 (51.32)
	Yes, just formality sake	13 (17.11)
	No, since there is no need to consider	3 (3.95)
	No, since the patient is not in a healthy condition	21 (27.63)
6.	Informing other relatives before employing the HN	

	Yes	51 (67.11)
	No	25 (32.89)
7.	Seeking other relatives' help before hiring the HN	
	Yes	12 (15.79)
	No	64 (84.21)
8.	Primary caregiver before the HN's arrival	
	Daughter	22 (28.95)
	Daughter-in-law	25 (32.89)
	Wife	5 (6.58)
	Husband	4 (5.26)
	None, since not ill before	17 (22.37)
	Sister	1 (1.32)
	Other relative	2 (2.63)
9.	Major/ dominant caregiver after HN's arrival	
	HN	69 (90.79)
	Both HN and Informal primary caregiver equally	7 (9.21)

Figure 4.1: Selection and hiring of the caregiver by a client

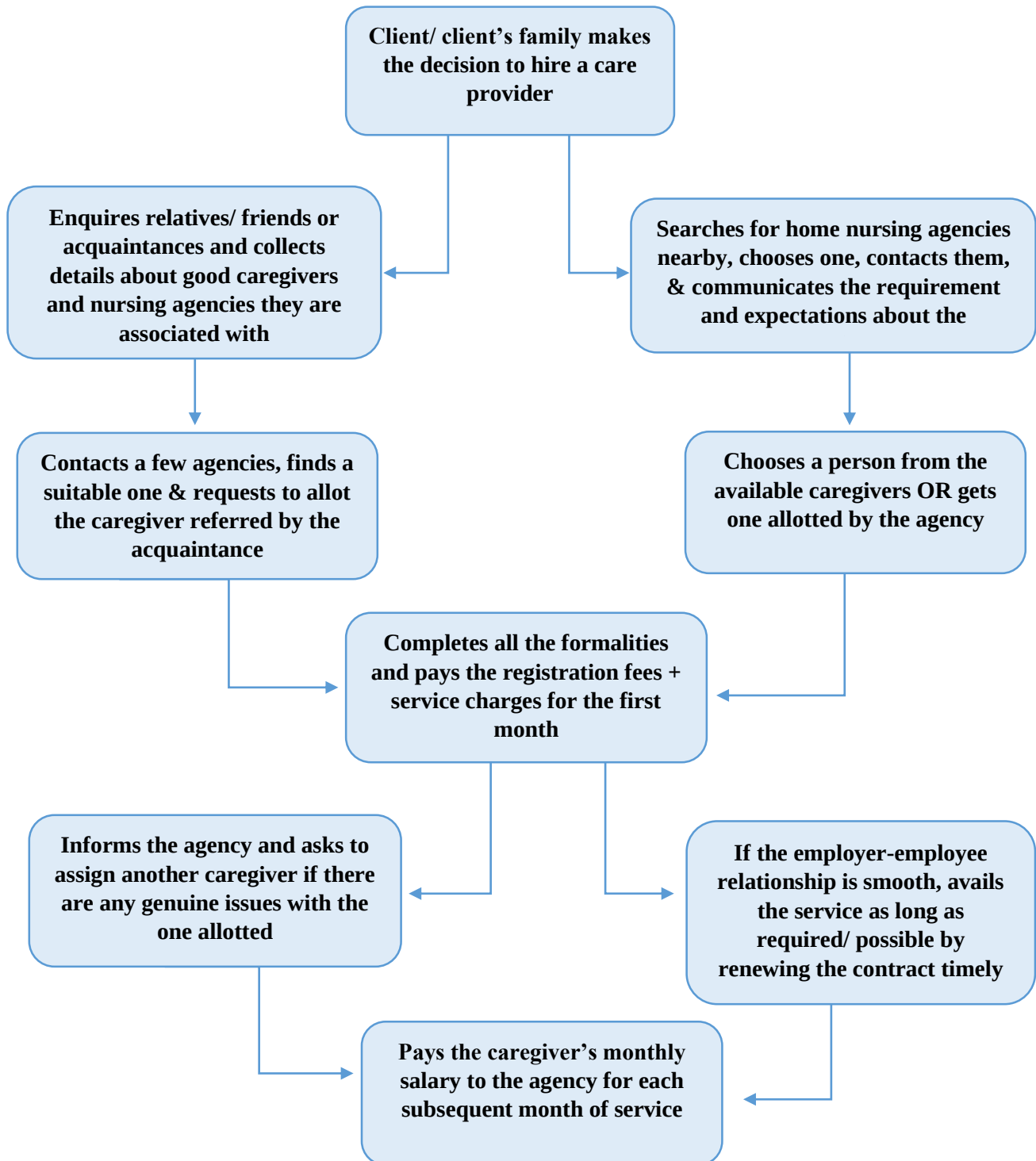


Figure 4.2: The indispensable qualities of caregivers

Indispensable qualities of caregivers

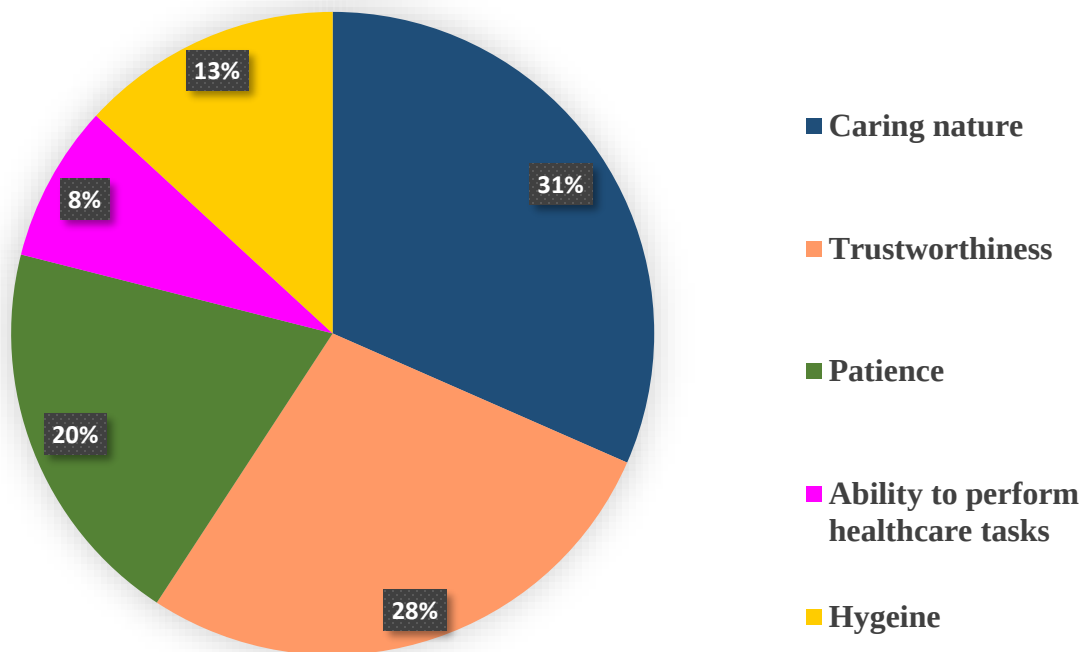
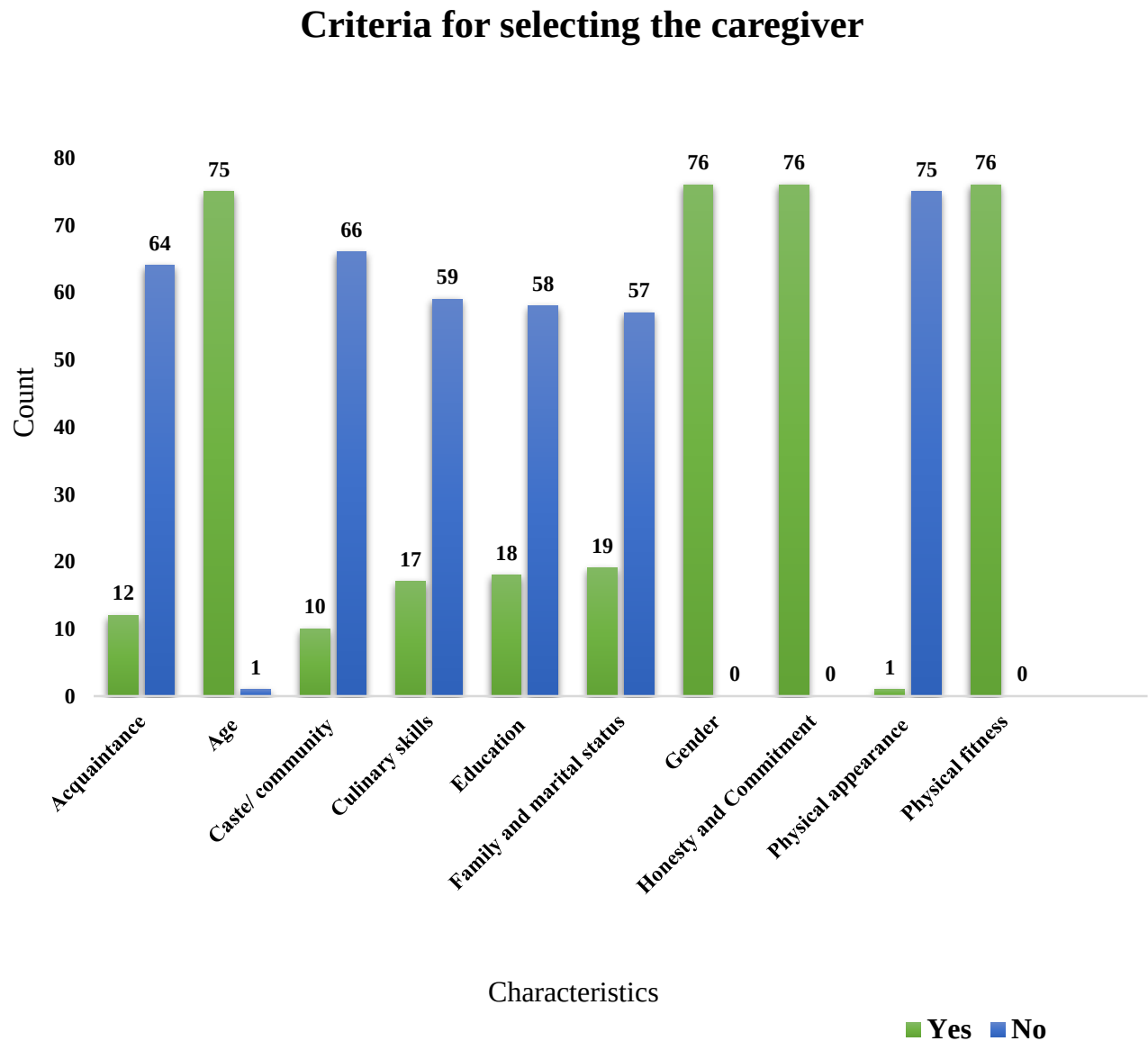


Figure 4.3: Criteria set by clients for hiring the caregivers



4.5 Domiciliary Care: Reasons and Opinions

Exploring the reasons behind the clients' decisions to purchase home care services can cast light on the factors that lead to the proliferation of the home care industry in the state. It is observed that a single reason or a combination of reasons prompted the clients to obtain the services. For more than half of the sample, the difficulty in handling the patient was one of the main reasons to hire a caregiver. Close to two-thirds of the sample expressed the complexity of managing work and caregiving. Several respondents commented on the tedious processes of bathing and toileting the patients. The uncooperative nature of the elderly patients owing to the shame of being nude in front of their adult children or daughters-in-law led some families to search for a formal caregiver to attend to the patient's personal care needs. While 12 respondents mentioned their busy work schedules as the reason, another seven justified that the paid employment of the womenfolk at their homes hindered their caregiving responsibilities. Eight informants stated the inability to provide care due to non-residence with the patient. The remaining ten mentioned the difficulties related to handling the patient's illness condition and behaviour as the reasons for hiring a caregiver. They opine that the formal caregiver has better expertise and experience in dealing with patients. A couple of respondents were of the view that they would not have hired a caregiver had they not been working. In their view, it does not require an outsider's help to take care of one's elderly parents or other family members. An informant named *Ajitha* admits that now that she works and her family has decent earnings, they can afford the services. Otherwise, she would have done it all by herself. She notes that since the HN is delegated the patient's complete care, she can concentrate on meal preparation and other household chores. She and a few other working women consider hiring the HN as a wise decision since they are able to continue their employment with the help of

the home nurse's services. However, it should be noted that none of the respondents hired a caregiver as soon as the patient became ill. The majority of the families tried providing care on their own. Only about 15% of the sample sought the help of their non-co-residing relatives.

In most cases, the decision to hire a formal caregiver was made when the process became physically demanding and tiring for the primary caregiver. Despite not seeking their relatives' help, above two-thirds of the clients' families involved their other relatives in their decision to hire the HN. Those who did not consider their relatives' opinions felt that nuclear families should decide. In the cases of postnatal care, it was planned to have a caregiver post the delivery because the family members did not have the know-how of postpartum care. Nevertheless, it is worth noting that one of the respondents pointed out that it has become a trend these days to hire a postnatal care specialist for a month or two. Since most of their relatives availed the services, the client also felt they should do the same. She stated that the agency allotted a person from the same community as theirs was a Muslim family. However, they wanted a Hindu caregiver since they are perceived to have better knowledge of postnatal care.

None of the respondents opined that home care was chosen to avoid hospitalisation. A few informants expressed contempt towards people who send their ailing relatives to residential care homes. The apprehension of being ridiculed by their relatives was also noticed from some narrations (for instance, Case-01). On the whole, it appeared that none of the informants preferred nursing homes and elderly care residences. Home care seems to be the apt choice for them when hospitalisation is not required since the patients can be at ease in their own homes. The reasons for choosing domiciliary care as opposed to hospital-based care were analysed. Only two clients stated hospital care being expensive as the rationale. They noted that home care is a cost-effective option even after facilities similar to the hospital are made available. More than two-thirds of the sample

felt that the patient's illness was not that severe to provide hospitalisation. A considerable number stated the patient's comfort as the reason for arranging care services at their homes. Five clients felt that it was better to have the patients receive home care so they could support the patients and monitor their health status. This mainly included the cases of patients disadvantaged by chronic illnesses. An attempt was made to identify if the respondents prefer end-of-life care (EoLC) at their homes. 53 families preferred to arrange home-based care for their relatives who suffer from terminal illnesses or nearing death so the latter could spend their final days at their own homes. The remaining respondents either did not have the patients approaching the end of their lives or hired the services for patients suffering from acute illnesses.

Upon analysing the clients' perceptions about the care provided at hospitals and caregiving in a home-based setting, a preference was found for the latter. Close to a quarter of the respondents considered domiciliary care a better option since the patients have more comfort in their own homes. Being in a hospital setting demands them to behave in a formal way that complies with organisational etiquette. More than 30% felt that compared to hospital nurses, home-based care providers are more approachable and better attached to the patients and their families. However, an equal number believed that hospital nurses are better in every aspect since they are qualified professionals. Eight others opined that their power relations with nurses in both cases are different. In a home care situation, the clients have more liberty to demand the care providers to perform their activities in a way they desire. The remaining four felt that home nurses are more considerate since they can concentrate on the needs of one patient at a time. The care recipients' thoughts on the downsides of not providing hospital-based care were examined. Close to two-thirds of the sample felt there were no issues since hospitalisation was not required for the patient. Twenty five respondents viewed that most home nurses are not academically nursing qualified, leading to a

compromised quality of care. The remaining three people expressed their worry that the patients' lives could be at risk if anything goes wrong with the healthcare procedures performed by the non-professional care providers. This implies that the shortcomings of home nursing were explained depending on the severity of the patient's illness. Though some clients believed that the caregivers were less competent in healthcare tasks, they still chose to employ them. They justified their decisions by stating that the patients' illnesses were not critical, and the caring nature of the individual matters more than their nursing expertise. Some of these clients required the home nurses to assist the patients with their personal care tasks, for which nursing experience on medically-oriented tasks hardly matters. A few did not bother about the aspect as the patient is aged and/or nearing death. While four respondents found home care to be a more comfortable option than hospitalisation, the other four stated that home care offers comfort and a feeling of belonging that they did not worry about the caregiver's expertise. It was tried to identify if the clients attempted to find caregivers who could perform better to improve the patients' health. While 14 clients reported that they had compromised for less equipped people as nursing qualified employees were unavailable, the remaining had similar reasons as above. This implies that many clients did not want the caregiver to be an academic nursing qualified person.

Discussed below is the experience of an informant named *Shaji* who had hired male caregivers for his father's care.

Case - 02

Shaji is an engineer by profession, and his wife is a teacher. A year back, when his father was alive and ailing, Shaji and his family had to rely on formal caregivers through home nursing agencies. The 87-year-old patient had suffered from some neuromuscular disorder, due to which

he lost the strength of his limbs. Shaji added that his father was tall and hefty, and he required the support of a physically strong person.

For around four years, the family had employed male caregivers. About 20 people from different age groups have worked for them, one after another. The last caregiver, the youngest of the lot, was 23 years old. The respondent notes that out of the twenty care providers, three were transmen. Considering the family members' safety, the caregivers and the patient were made to stay in an outhouse. Shaji used to monitor his father's condition daily.

The caregivers used to attend to the personal care tasks of the patient, give the medication and keep the room clean. The patient did not require hospitalisation, but his caregivers had accompanied him whenever he wanted to be taken to the hospital. Towards the end, the salary paid to the care provider was 18,000 rupees. The family opines that around 60% of the people had taken good care of the patient. The rest had created some issues, did not maintain proper hygiene, or had smoking and alcohol consumption habits. Shaji and his family always tried to maintain a safe distance with all caregivers, even though some of these men were very well behaved. Also, they did not stay in contact with any of their previous employees. Shaji's wife did not interact much with any of these men as she was afraid it would bring her a bad name among her relatives and neighbours.

In Shaji's view, a caregiver's job is easier for men since they do not have to toil hard or involve in much physical labour but earn the same amount of money that they can make from other work, such as daily wage labour. In addition to this, they are provided with a safe place to stay and proper food at the client's house. The job seems to be a safer option for transgender people as they just have to gain the acceptance of one family and need not interact with many, encounter

difficult situations or face discrimination, which they otherwise might have experienced in other jobs.

The family admits that the patient's health and psychological condition had improved a lot after the caregivers provided him physical and emotional support. Also, they acknowledged that the home nurses who work sincerely and impact the lives of the patients they care for are a boon for clients like them.

Table 4.4: Reasons to use home-care services

Sl. No	Characteristic	Numbers and Percentages (in parentheses)
1.	Reasons to hire a home nurse	
	Family members busy with their work	12 (15.79)
	Women in the house are formally employed	7 (9.21)
	Children settled abroad/ away from the patient's residence	8 (10.53)
	Difficult for the kin to handle the patient	10 (13.16)
	Difficult for the kin to handle the patient + family members busy with their work	29 (38.16)
	Home nurses are better equipped than the family members	10 (13.16)
2.	Reasons to provide home-based care	
	The patient can be more comfortable since it is own home	14 (18.42)
	Hospital-based care is expensive	2 (2.63)
	Not happy with hospital settings and hospital staff	0 (0)
	Family members can be in touch with the patient	5 (6.58)

	Illness is not that severe	55 (72.37)
3.	Major differences between hospital and home-based care	
	Can be at ease when the setting is home	17 (22.37)
	Home nurses are more close, approachable, friendly, and attached to the patient & family members	24 (31.58)
	Power relations of clients with both the nurses are different	8 (10.53)
	HNs are more caring as they provide personalised care	4 (5.26)
	Hospital settings and staff nurses are better	23 (30.26)
4.	Perceived drawbacks of not providing hospital-based care	
	N.A. since not required for the patient	48 (63.16)
	Unqualified nursing personnel in home-based care	25 (32.89)
	Patient's life at risk sometimes	3 (3.95)
5.	Reason to opt for home-based care despite the downsides	
	The patient's illness is not that serious	62 (81.58)
	The nursing expertise of the care provider does not matter	4 (5.26)
	The patient is aged and will anyway die soon	4 (5.26)
	Comfort and a feeling of belonging at home	2 (2.63)
	Hospital care is more expensive than home care	4 (5.26)
6.	Reason to have a less competent/ under-equipped caregiver	
	Qualified personnel are unavailable	14 (18.42)
	Hiring qualified nurses is expensive	0 (0)
	The patient's illness is not that serious	51 (67.11)
	Nursing education of the care provider does not matter	8 (10.53)
	The patient was nearing death, so there was no need to have a qualified nurse	3 (3.95)

Plate 4.1: A chronically ill patient availing home nursing services



Source: Fieldwork

4.6 The Proliferation of the Home Nursing Industry: Does Family Type Have a Role?

One of the reasons home nurses are hired is the primary caregivers' difficulty in allocating enough time for the caregiving process due to their employment. Almost all of the patients were found to have their relatives reside in the same households. There were a few elderly clients who were staying with the families of their adult children on a rotational basis. The elderly had to undergo this since all their children are employees who have busy lives. Five elderly clients stayed

with their spouses in their own homes and not with their children or other relatives. This happens when the adult children are either settled in faraway places or a different home closer to the ancestral homes where their elderly parents reside. These clients are counted under the category of the nuclear family.

Many assume that the younger generation does not spend enough time with their ailing and elderly parents in today's world. Thus, it was decided to explore if the family types of the clients have a relation with the purchase of home care services. The data revealed that the family types of the respondents are more or less nuclear. Thirty four families are clearly nuclear since they have members of one or two generations. The cases of five elderly patients who live with their spouses mentioned above have been included in this category. When the elderly couple stays together, the healthy person takes the role of the primary caregiver for the ailing spouse. It is mainly the wives who carry out the informal caregiving for their spouses. The remaining 42 clients were part of extended nuclear families that consist of three generations living in the same household. Since most of the cases in the study are of patients aged above 50 years, the majority of them were found to be residing with their adult children and grandchildren. None of the respondents was part of joint families. One of the reasons for this could be the lesser prevalence of the joint family system in Southern and central Kerala than in some districts of Northern Kerala.

In the study area, there is a preconception that nuclear families are the main customers of domiciliary care services. In other words, the rise in nuclear families is considered to have boosted the home nursing industry in Kerala. Owing to this, it was decided to explore the respondents' opinions. While about 65% of the clients favoured this perception, the others believed that the shift towards nuclear families has not resulted in the mushrooming of home nursing agencies. The latter opined that the industry's growth is not connected to the family types of its customers. The clients

were also enquired if they would not have hired a home nurse had they been part of joint families. Over half of the sample believed that there would have been no need to have a formal care provider if there were enough members in the household to share the responsibility. The remaining felt that the family type did not affect their decision to hire the care provider. They consider the formal care providers' services to be the need of the hour. It is either because the family members cannot sacrifice their time on the caregiving process while employed, or they do not want to overburden the family member who carries out most caregiving tasks. In such situations, the services of formal caregivers become inevitable.

Presented below are a few case studies.

Case - 03

Dileep is a school teacher who purchased home nursing services to assist his mother-in-law, who was suffering from mental illness and other health issues. His wife runs a beauty parlour and would be away from home daily. Due to their inconvenience, the family had to employ a formal caregiver. Within a month of availing the services, two caregivers left, and a third one is on duty. Dileep admits that it was hard for the first two to adjust to the patient's character and her angry outbursts. The family members also had difficulties handling the patient as she behaved angrily with them. The third caregiver seems to be very understanding and is empathetic to the bedridden patient. Dileep is of the sentiment that the home nurse's services are inevitable for their family as they are a working couple. He adds, "our situation will be tough if the home nurse is on leave even for a single day".

Case - 04

Jasmine is a nurse who works at a district hospital, and her husband is a businessman. To take care of the latter's father, they hired a caregiver. The patient had a stroke a year back and is paralysed on the right side of the body. He also suffers from memory loss. The patient's wife was alive, but since she too was suffering from some age-related illnesses, there was a need to have the support of a person.

As she was apprehensive about employing a stranger, Jasmine's family did not hire an employee through a home nursing agency; instead, they chose one with whom they were acquainted. Even though the patient was a male, the family wanted a female caregiver due to the fear of letting a strange man stay in the house. The respondent has two girl children, and because of safety concerns, they felt it is better to have a female caregiver. They wanted a caregiver who was middle-aged and married. Since Jasmine is a professional nurse, she was not particular about the caregiver's knowledge of nursing tasks. She used to monitor the caregiver's work and teach her to perform certain tasks such as administering insulin and monitoring blood sugar levels.

She recalls that the caregiver initially had issues dealing with the urine and excrement of the patient but got used to it later. The home nurse used to call the patient 'Papa' and treat him like a parent. Despite the patient's memory loss issue, he used to respond to the caregiver's voice at times.

Jasmine does not think nuclear families have given rise to the home care industry. She views that even in joint families, if women are employed, they will need the support of formal caregivers. She believes that the caregivers who are committed to the job and well equipped with caregiving tasks are a better fit in this field. She adds that academically nursing qualified people

would improve the status of home nursing. Despite this aspect, she does not forget to recognise the care providers who take such good care of the elderly patients in the absence of their kith and kin.

Case - 05

Aji works as a medical doctor in Angola while his family resides in Kerala. His wife, a teacher by profession, finds it hard to manage her work and the care of Aji's mother, who has cancer. The patient is bed-bound and has stopped speaking for almost three months.

A year has passed since the family started using home nursing services, and it is the third caregiver who is serving the patient now. Aji wanted a care provider who is aware of the basic nursing tasks. He accepts that it is hard to find a qualified nurse, so one has to look for people who have at least experiential knowledge. His family did not want the person to perform tasks unrelated to the patient's care. They have instructed her to rest or pursue leisure activities when she gets done with her work. Still, when she has free time, she often helps Aji's wife in the kitchen by chopping vegetables or washing utensils.

He considers that the country's home care industry is not systematic as it does not have an accredited curriculum or well-trained staff. He remarks that every caregiver must be aware of all healthcare procedures. Empathy, patience, and good communication skills are the qualities he looked for in a care provider. The caregivers should adjust to patients' mood swings and aggressive nature, especially those who suffer from mental health conditions.

Dr. Aji recollects that the patient had initial difficulties with the strange caregiver, but she got along in a month. His family was quite satisfied that the patient was comfortable in the

caregiver's company. Though the patient's condition did not improve much in this one year, it has not become worse either. He does not consider weakening family ties and the growing number of nuclear families to be the reason behind Kerala's burgeoning home nursing industry. He believes that the changing socio-economic conditions of the families have resulted in his shift. According to Dr. Aji, the services of home nurses have become essential for families of emigrants. When his family did not have the time for his mother's care, home nurses came to their rescue.

For this reason, he thinks every client should recognise and reward good caregivers appropriately. They deserve respect and recognition for their services. Sadly, several customers do not treat them well or provide them with good facilities. Some people do not provide the home nurses with face masks or gloves. Aji's family ensures that the caregiver is given every possible facility that makes their job safer and more accessible.

Case - 06

Shylaja is a homemaker who has been taking care of her 82-year-old mother. The latter had locomotion troubles owing to obesity. Since Shylaja could not handle the patient alone, the family decided to hire a home nurse. They wanted to hire a middle-aged woman who could be with the patient around the clock to constantly monitor her, provide timely food and medicine, and assist her daily activities. It was assumed that someone in their fifties would efficiently meet an elderly parent's needs. They preferred someone who does not have many familial obligations, preferably a widow. The family did not want to involve the caregiver in any activity unrelated to the patient's care. Even after the HN's arrival, Shylaja did not withdraw from the caregiving process despite the former being the primary caregiver. She ensured that she offered whatever

help the HN required. Though theirs was a Hindu family, they were allotted a Christian employee by the home nursing agency. However, they did not have any issues with the caregiver spending time for daily prayers or going to the church for Sunday mass. The family was content with the caregiver's services and remarked that she was very hygienic. When the patient was required to undergo physiotherapy during the HN's tenure, she assisted the physiotherapist in letting the patient practice some exercises. Shylaja recognises that the HN helped reduce her caregiving burden a great deal.

Although the patient had male children, she preferred to stay with Shylaja's family since she had conflictual relationships with her daughters-in-law. Nevertheless, all children contributed to the monthly home nursing expenses. These bitter relationships and conflicts could be one reason why Shylaja thinks that the services of home nurses are required even by joint families of the present times.

Case - 07

Sheeba is an Ayurvedic doctor, and her husband is an engineer. They have two school-going children. To look after her 72-year-old mother-in-law, Sheeba has been employing caregivers for the past three years. The patient suffers from cervical myelopathy, due to which she is paralysed below the waist. When the bedridden patient became obese, Sheeba could not care for the patient all by herself. Since then, the family has had almost 20 caregivers, one after the other. Over time, the patient has undergone physiotherapy exercises, with the help of which she could return to a healthy weight. The home nurses have been supportive in this transformation. They used to assist the physiotherapist and help the patient perform the exercises as instructed in

the latter's absence. Since the family has a housemaid, they never required the home nurses' help with household chores. Sheeba admits that their family cannot function properly without the help of a caregiver. For them, the home nurse is a proxy who helps tackle an otherwise unmanageable situation. In her words, "nuclear families, especially elderly parents who have their children settled elsewhere, require the services of paid caregivers. As they live in 'homes without children', these caregivers become surrogate children to the elderly ailing parents".

Table 4.5: Family type of the clients

Sl. No	Characteristic	Numbers and Percentages (in parentheses)
1.	Family type of the employer	
	Nuclear (2 generations)	34 (44.74)
	Extended nuclear family (3 generations)	42 (55.26)
	Joint	0 (0)
2.	Relation between family type and HN industry's growth	
	Yes, nuclear families have given rise to the industry	49 (64.47)
	No, family type does not impact	27 (35.53)
3.	Relation between family type and decision to hire the HN	
	Would not have hired a home nurse had it been a joint family	42 (55.26)
	Caregiving services is a need in today's times irrespective of the family type	34 (44.74)

4.7 Expectations and Satisfaction with the Caregiving Services

In any employee-employer relationship, each party would have certain expectations about the other. In the chapter on caregivers, it has already been discussed how the home nurses want them to be treated by their patients and families. Similarly, it was decided to understand how the clients like the care providers to behave with them and whether they encourage friendly or formal relations with the care providers. More than three-fourths of the sample regarded that the caregivers should be treated as family members and given enough freedom to involve in their household matters. The remaining people liked to consider the caregiver as someone who should not be entertained in anything unrelated to caregiving. To know about the care providers' role in the patients' treatment, the clients' opinions on the services of the former were sought. It was found that barring seven cases, all the HNs were assigned a greater responsibility of the patient's care by the employer families. Several clients stated that the home nurses actively took part in the process and assumed the role of primary caregivers, thereby helping to improve the health conditions of the patients. About 40% of the sample responded that the care providers tried their best but could not succeed since the patients were nearing death. However, five clients opined that their care providers did not look after the patient well.

As the care providers not only take care of the healthcare aspect of the patient but also provide emotional support and companionship, it was attempted to capture if the clients ever felt that the home nurse's presence was able to bring a positive impact on the patient's life and health. More than two-thirds of the clients responded affirmatively and added that the care providers had helped make the patients' daily lives better. One of the respondents stated, "even when we could not spend much time with my mother, she (the caregiver) used to make sure that my mother does

not feel lonely or sad”. Several others also made similar comments which testify that most care providers spent time with the patients, listened to them, and tried helping them in whatever possible ways. The remaining informants who conveyed that the HN did not positively impact the patient’s life must have experienced the services’ inefficacy at improving the patients’ health, the patients’ demise, or bitter relationships with the caregiver.

The respondents’ satisfaction with the services provided by their caregivers was examined. The ratings ranged from 1 to 5 (1 being least satisfied and 5 most satisfied). Clients who have had multiple caregivers gave an overall rating for the services and not individual ratings for each person employed. The ratings seemed to be connected to the clients’ relationships with the caregivers. The commitment and sincerity their respective caregivers had for the work they performed, the support they provided in difficult times when family members could not do their part, and the formation of friendly or family-like bonds with the caregivers were reported to be the primary sources of satisfaction. None of the respondents expressed extreme dissatisfaction with the services. Though nine people seemed dissatisfied, the greatest number was moderately satisfied. While 28 were satisfied with the work of their caregivers, the remaining four seemed to be exceptionally satisfied with the services they received. A Pearson correlation was conducted to find any connection between the client’s family’s closeness with the caregiver and satisfaction with their services. The two variables were found to have a moderate positive correlation ($r=0.305$). This indicates that the clients’ families’ closeness with the caregivers impacts the satisfaction levels of the services. However, several other factors such as improvement of the patient’s health after the HN’s arrival, personal characteristics of the HN, the patient’s rapport with the HN also seemed to affect the satisfaction levels. The test results have been presented in the table below.

Table 4.6: Correlation between closeness of the HN & clients and service satisfaction

Correlations		How close is the home nurse with the patient and the family members/?	Satisfaction levels
How close is the home nurse with the patient and the family members?	Pearson Correlation	1	.305**
	Sig. (2-tailed)		.007
	N	76	76
Satisfaction levels	Pearson Correlation	.305**	1
	Sig. (2-tailed)	.007	
	N	76	76

**. Correlation is significant at the 0.01 level (2-tailed).

Here is the case of a satisfied client in a nutshell.

Case - 08

*Beena, a teacher by profession, is a childless widow. She had employed a caregiver for three months while on bed rest after undergoing a hysterectomy. The caregiver cared for her as if a mother cared for a daughter. Beena's mother is not alive, but the caregiver did not make the absence felt. She was the one who stayed with her as the bystander in the hospital at the time of her surgery. Once they were discharged from the hospital, Beena did not seek any of her **relatives'** help as she found the caregiver a trustworthy person. They both developed a good bond, and the*

home nurse was unhappy to end the contract and leave. She still stays in touch with Beena and meets her occasionally.

Table 4.7: Expectations and satisfaction with the caregiving services

Sl. No	Characteristic	Numbers and Percentages (in parentheses)
1.	How should the home nurses behave with the patient and family?	
	Like a kin member-involve in family matters	67 (88.16)
	Like a caregiver- just focus on patient care	9 (11.84)
2.	HN helping to improve the patient's condition	
	Yes	40 (52.63)
	No	0 (0)
	Yes, tried but failed	31 (40.79)
	No, since they did not care properly	5 (6.58)
3.	HN's presence bringing a positive impact on the patient	
	Yes	52 (68.42)
	No	24 (31.58)
4.	Satisfaction with the HN's services	
	Very dissatisfied	0 (0)
	Dissatisfied	9 (11.84)
	Moderately satisfied	35 (46.05)
	Satisfied	28 (36.84)
	Very satisfied	4 (5.26)

4.8 Remarks About the Caregivers and Home Nursing Industry

The clients' opinions on the home-based nursing industry and the nurses they hired were analysed. The respondents were required to cite a major advantage and a major drawback of the services. While discussing the most beneficial aspect, more than one-fourth of the clients stated that an honest care provider is an advantage since they can leave the patient with them when they go to work. Almost an equal number stated that home nurses share the caregiving burden and become a helping hand to women who are otherwise the primary caregivers for their ailing relatives. Close to one-fifth were happy that the home nurses performed all the tasks related to patient care without any inhibition. By this, they specifically meant that the HNs did not worry about dealing with the urine or excrement of the patient. Four clients revealed that HNs are a boon for patients who do not have family members' assistance. They acknowledged loving and caring HNs who genuinely try to improve the patients' lives. The remaining clients were impressed that their care provider helped them in household chores and behaved like a family member. Besides this, the clients specified some disadvantages based on their experiences with the home nurses they have mingled with. Most clients revealed that several home nurses are not sincere and committed to the work. Some were unhappy with the fact that not all HNs are trained in health care tasks. A few mentioned the morally weak characters of some of the female caregivers as the main aspect they disliked. The other problems mentioned were the interference in personal matters of the client, involvement in theft, the ill-treatment of the patients, and their excessive mobile phone usage. It is worth noting that ten clients did not remark any drawbacks since they could have been satisfied with the home nurses' services.

The home nurses are perceived differently by people across the study area, and so do the clients who formed the sample of this study. While many have negative perceptions, stereotypical

notions and prejudices, none believe that all the home nurses are committed to the work. Home nursing, being a female-dominated industry, has a small proportion of male care providers too. However, all the clients neglected this element, and their responses testify this. More than half of the clients believe that home nurses are people from economically poor backgrounds searching for jobs. Almost 40% understand that the industry consists of women from broken families who took up the jobs to sustain their lives. It is worth citing that the standpoint of one of the clients is that care providers are bad women who are ready to do anything for money. This response throws light on the widespread tendency to generalise things and blame an entire community for the wrongdoings of some of the members. Moreover, only two clients perceive that the caregivers chose the job due to their interest to look after the ailing. Almost all the informants viewed that these people stepped into the caregivers' shoes only to support their lives financially.

Since there have been a few instances of home nurses involved in theft cases that appeared in newspapers, it was decided to examine if the clients had any such incidents with the home nurses they hired. Four clients had experienced such cases where the care providers tried to steal gold ornaments, money, or other valuables from their homes, and the police later dealt with them. Half of the clients opined that theft cases often happen under the mask of home nursing services. Close to 20% were of the view that such incidents never occur. While one-fourth of the sample alleged that such cases occur sometimes, the remaining people did not comment as they have not personally experienced it or heard from any of their acquaintances.

As most of the clients pointed out both positive and negative aspects of the home-based care industry, it was decided to ask how far they think the care providers deserve the title 'home nurse'. Albeit the English term 'home nurse' is used to refer to in-home care providers across the state, Chapter 2 reveals that several caregivers do not like to be addressed by the term. Most clients

believe that the term does not suit all, but only those caregivers capable of performing the healthcare tasks. This implies that individuals who perform the duties of home health aides deserve the title ‘home nurse’. Only ten clients were convinced that the label suits all the caregivers very well. More than one-fourth viewed that it is appropriate to an extent since they perform several duties related to the patients’ care needs. These clients felt that even if the majority of the in-home caregivers are not academically qualified, they perform some healthcare tasks either due to the training they received or due to the experiential knowledge they gained from the field. Seven people mentioned that terms like caregivers, helpers, attenders, or bystanders are preferred to ‘home nurse’. The Malayalam equivalent of these terms are *parichaarakar* (പരിചാരകർ), *sahaayikal* (സഹായികൾ), *rogiyude koottu nilppukar* (രോഗിയുടെ കൂട്ടുനിൽപ്പുകാർ).

Somehow, these informants admit they never use these terms, but find it convenient to address the caregivers by the title ‘home nurse’. In the words of a respondent named *Dr. Aji*, “The term ‘Home Nurse’ better fits individuals who are nursing qualified. However, the tag has given more dignity to the caregivers, and so the term should replace other terms like helper or maid”. Another client named *Sheeba*, a doctor by profession, suggested that a term such as ‘care assistant’ would be a better choice since it will remove the ambiguity caused by the word ‘nurse’ in the job title.

To identify who, according to the clients, is a ‘home nurse’, they were provided with two choices – a person who attends to the patient’s personal care needs or someone who can take care of both the personal care and healthcare needs. Around 80% of the clients chose the latter. The remaining stated that as long as a care provider attended to the patient’s personal care needs by residing in their home, the meaning of the term ‘home nurse’ is fulfilled, thus confirming the job title apt. It was also tried to examine if the care recipients liked the caregivers to offer housekeeping

support. While two clients mentioned that it was mandatory, it was considered a desirable activity by 13 people. The majority (nearly two-thirds) believed that the decision to help or not help the client's family in the household activities is up to the care provider. If they wish to contribute, then they would not discourage them. These clients did not compel the care providers or ask for their help but were happy if the caregivers voluntarily helped them in the household's day-to-day activities. It was interesting to know that 13 clients did not want the caregivers to perform any duty that is not directly related to the patient's care. The respondents were inquired if the caregivers should be able to perform health care tasks. All but two wanted the HNs to care for the patients' healthcare needs. However, surprisingly, many of them perceived the caregiver's ability to perform such duties as a desirable quality and not a mandatory one. Almost an equal number of clients consider the knowledge of healthcare tasks as a must for a home nurse. The data reveals that the caregivers of twenty four clients did not perform any healthcare tasks that fulfilled the patients' medically oriented needs. These people's role is akin to home care aides' role mentioned in the first two chapters.

Presented below is the case of a respondent whose mother has been served by several HNs.

Case - 09

Thibeen's family had to depend on home nursing services for his mother, who has been suffering from Alzheimer's disease and diabetes. They have been availing the services for almost six years, and Thibeen recalls that about 15 in-home care providers have worked for them, one after the other. The tenure of each of these people ranged from two months to six months.

Thibeen and his wife are government employees. His siblings and their spouses are working too. Due to this reason, a formal caregiver had to be employed. They wanted to hire a middle-aged woman who knew healthcare tasks and could help with the household chores. Since the patient was bedridden, they were concerned about hygiene issues. Thibeen's wife constantly checked the caregiver's activities to see if diapers were changed regularly, catheter care was correctly done, and the patient was free from bedsores.

He pointed out that several caregivers were committed and passionate about the work they performed. However, some did not properly care for the patient. He recalls a lady dismissed from the job since she had scolded his mother and mistreated her. He opines that the majority of the employees have been good to them. A couple of the previous caregivers are still in touch with Thibeen, and they make calls once in a while to enquire about the patient. Since the patient has a mental illness, he cannot really agree that there has been an improvement in the patient's condition after the caregivers have started attending to her. However, he considers that the home nursing industry has benefited nuclear families in general and the patients' informal caregivers in particular.

Table 4.8: Remarks about the caregivers and home nursing industry

Sl. No	Characteristic	Numbers and Percentages (in parentheses)
1.	A major advantage of the HNs/ HN industry	
	Caring and loving attitude towards patients	17(22.37)

	A helping hand for working women	18 (23.68)
	An honest HN is an asset- can leave patient and home with them	21 (27.63)
	Help in household chores	1 (1.32)
	HNs are a boon for patients who do not have family members' assistance	4 (5.26)
	HNs perform all tasks without any inhibition	15 (19.74)
2.	A major drawback of the HNs/ HN industry	
	Not all are committed/ sincere in the job	29 (38.16)
	Not all HNs are trained in health care tasks	11 (14.47)
	Interference in personal matters of clients/ privacy issue	3 (3.95)
	Theft issues	2 (2.63)
	Do not adjust with the client's family members	3 (3.95)
	Nothing as such	10 (13.16)
	Excessive phone usage	5 (6.58)
	Some HNs have weak moral characters	10 (13.16)
	Ill-treatment of patients	3 (3.95)
3.	Popular perceptions about home nurses	
	People from an economically poor background in search of jobs	43 (56.58)
	Women from broken families to sustain their lives	30 (39.47)
	Bad women who are ready to do anything for money	1 (1.32)
	People who are interested in looking after ailing, those with a service ethic	2 (2.63)
4.	Does the term HN suit the care provider?	
	Very well	10 (13.16)
	To an extent	24 (31.58)
	It does not suit all, but some people	8 (10.53)

	Suits those who can perform healthcare tasks	27 (35.53)
	Some other terms like caregiver/ helper suits better	7 (9.21)
5.	According to the client, who is an ideal ‘home nurse’?	
	Anyone who can care for the patient’s personal care needs	15 (19.74)
	Anyone who can care for the patient’s personal care & health care needs	61 (80.26)
6.	Should the caregiver perform the client’s household tasks?	
	Yes, desirable	13 (17.11)
	Yes, mandatory	2 (2.63)
	No	13 (17.11)
	According to the HN’s wish	48 (63.16)
7.	Should an HN be able to perform health care tasks?	
	Yes, desirable	36 (47.37)
	Yes, mandatory	38 (50.00)
	No	2 (2.63)

4.9 Discussion

This chapter has depicted the cases of some patients and families that purchased domiciliary care services. The age categories and illnesses of the patients that comprised the sample have been analysed. Close to three-fourths of the patients are aged above 70, and the greatest number of people were seen suffering from age-related illnesses and other lifestyle diseases. The primary caregivers of the patients mainly were their daughters and daughters-in-law. Less than one-fourth of the sample were male patients, and in none of the cases of elderly males were their spouses, the major caregivers. This is because spouses were either deceased or not healthy enough to take up the role. This finding is not in line with Wilcox and Taber (1991), who

argue that “wives and daughters are often the primary caregivers” (p.258). Olagundoye and Alugo (2018) define “secondary caregivers as people who usually do not live with the care receiver but give support and assistance in the form of finances, visits or other tasks” (p.5). As far as the present study is concerned, a couple of respondents acted as secondary caregivers due to their non-co-residence with the patients.

Existing research demonstrates that “most patients find it very rewarding to have their loved ones around to care for them, and to accompany them through their healing process” (Olagundoye and Alugo, 2018, p.10). Nonetheless, the caregiving process brings with it certain challenges. According to Chandran, Corbin & Shillam (2016), “the family caregivers of chronically ill patients are likely to experience serious issues that affect their health and well-being” (p.163). Ward-Griffin’s (2001) study too reveals that “female family members, who assume the vast majority of informal caregiving responsibilities, bear tremendous physical, emotional, and economic costs” (p.64). Similarly, research by Gupta (2009) on the caregiving of the elderly in India discusses the burden experienced by women caregivers. The author notes that “the Indian female caregivers may feel that they have no choice but to provide care for their in-laws as that is a normative custom in India” (Gupta, 2009, p.1050). This custom is prevalent in the present study area, and the data testifies that daughters-in-law were the primary caregivers in a good number of cases. It should be noted that daughters were the primary informal carers of elderly patients who lacked male children. However, after the arrival of the HNs, most of these primary caregivers were seen stepping down from the role. This is reflected in the clients’ confirmation of HNs becoming the dominant caregivers in more than 90% of the cases. Only a handful of cases did the significant others play a caregiver’s role, taking efforts greater or equal to that of the HN.

Gantert, McWilliam, Ward-Griffin & Allen (2009) observed: “family caregivers obtaining necessary respite after the arrival of in-home providers” (p.51). Stoller (1989) views that “formal providers may also reinforce family caregivers’ confidence, validate their need to take time for themselves, and ease the pressures of long-term care decision making” (p.4). This was confirmed by some of the respondents who acknowledged the HN’s contribution in the exhausting process of caregiving as a relief. A few others reported better focusing on their employment or other household activities after hiring the HN. Tennstedt, Crawford, & McKinlay (1993) believe that “formal caregivers are supporting and sustaining the informal caregiving arrangement or providing the care during the disruption of this arrangement to keep the elderly in the community” (p.621).

A report by International Labour Organization reveals that “changes to family structures, higher care dependency ratios and changing care needs, an increase in the level of women’s employment increased the demand for paid care work in certain countries” (Addati, Cattaneo, Esquivel & Valarino, 2018, p.xxviii). Though most of the clients in the present study support the view that the shift to nuclear families has boosted the home care industry, in a considerable number of cases, the decisions to hire the caregiver were not influenced by the family types. These people believe that domiciliary care services have become commonplace regardless of the family type, thereby proving that other reasons such as the preference to seek professional help, employment of the primary caregivers and their unavailability to render care impact the decision to purchase the services. Recent research by Ugargol & Bailey (2018) underscores “Kerala’s demographic transition and emigration of primarily male adult children” who leave behind their elderly parents and other family members. The authors discussed “daughters-in-law who sacrifice their careers to take up caregiving roles” (Ugargol & Bailey, 2018, p.194). However, the present study observes that the employment of home nurses brings about a shift in this scenario.

Stoller (1989) claims that “working women cannot themselves provide hands-on care during the hours they are at work, but the income they receive from working may increase their ability to finance home care” (p.48). It has been acknowledged that “outsourcing of domestic services might reduce care and time deficits of the relatively well-off segments of the society” (Estevez-Abe & Hobson, 2015, p.143). A handful of clients’ relatives in the current study considered it a sensible decision to hire a caregiver who could be their proxy. They voice that though the working women create a care shortfall in their families, their employment fetches enough money to employ care workers who can provide the requisite services. In the current study, the purpose of hiring the HNs in some cases was identified as providing emotional support and companionship to the patients besides the routine assistance with ADL or IADL. It is worth noticing that a few family caregivers (especially daughters-in-law) had experienced difficulties handling the elderly patients’ uncooperative behaviour during bathing and toileting them, or had some hesitation to seeing the bare bodies of the patients. Most of them did not want to carry out such tasks if the patient was of the opposite gender. They opined that the issue was sorted once they could shift this responsibility to the HNs. On the whole, it appears that the major rationale behind hiring the HNs is to provide the primary caregivers enough time to take care of their personal and professional lives and delegate the caregiving duties that they find uncomfortable or tiresome.

The reasons for the preference of home care were found to be less severity of the illness, the patient’s comfort and a sense of belonging due to receipt of the services in their residence, the HNs’ ability to provide individualized services, and family members’ ease to monitor the caregiving process. In research by Rajan and Arya (2018), “elderly was found constituting more than 12% of Kerala’s total population, and about 0.3% of these elderly preferred staying in old-

age homes to staying with family members” (p.80). This shows that the majority of the aged in the state choose to stay with their families. The present study also confirmed this, and the respondents were seen disfavours institutionalisation of the elderly patients into care homes. It was also a shame for some families to have their ailing relatives sent to residential care homes. Penning and Keating (2000) too remark that “the placement of older adults in formal care settings symbolised the failure (and unwillingness) of families to support their elderly kin” (p.77). Olagundoye and Alugo (2018) predict that “need and demand for home care will rise exponentially due to population ageing and the increasing trend of non-communicable diseases (NCDs)” (p.3).

In the present study, specific criteria were employed by the care receivers while hiring a caregiver. While characteristics of the caregiver such as gender, age, and physical fitness were prime to all the clients, aspects such as physical appearance, caste, educational qualification, marital status and acquaintance with the person were of concern to a fewer number. Despite stating that the caste of the caregiver was not a selection criterion, almost half of the clients had people from their own castes working for them. A disinterest in hiring persons belonging to lower castes, tribes, and Muslim communities was noted in some cases. A preference for female caregivers for the care of male patients was observed, one of the reasons for this being the unguaranteed safety of the family members due to employing a strange male caregiver. It was also identified that in some families with male caregivers, the patients’ female relatives did not interact much with them for fear of being accused of illicit relations. The case of an elderly patient who stayed along with the caregiver in an outhouse has already been elaborated.

As far as the clients’ satisfaction with the services is concerned, the caregivers’ relationships with the clients’ families seemed to be a contributing factor. Most care recipients displayed moderate to good satisfaction resulting from the caregivers’ affection and concern for

the patients. However, some clients complained about several caregivers' lack of sincerity, incompetency in the performance of medical care tasks, ill-treatment of the patients, involvement in theft, over usage of mobile phones, and female workers developing illicit relations with the patients' male relatives. A study on challenges to home care quality conducted in the U.S. reported problems such as "home health aides' lack of knowledge; unavailability of qualified personnel; worker insensitivity, disrespect, or intimidation of client; intentional injury or abuse of clients; as well as theft and financial exploitation" (Kane, Kane, Illston, & Eustis, 1994, p.77). The authors highlighted the "importance of compatibility between the home care worker and the client as a goal for home care" (p.82). Similarly, the clients in the present study were also found appreciating the HNs' character and their bond with the patient more than their healthcare skills and knowledge. Some were pleased to find the patient comfortable and happy in the caregiver's company. Moreover, they were seen favouring the caregivers' experiential knowledge and not their formal education. In research by Büscher et al. (2011), evidence is provided for "technical incompetence of the caregivers undermining and prohibiting a trustful relationship" (p.711). A couple of clients in the current study were disturbed by the HNs' incompetence and reported that it builds a fear that the patient's life can be at risk if any nursing procedure is carried out wrongly. However, a greater number of informants were seen considering the know-how of such technical tasks to be a desirable attribute of the caregiver rather than a mandatory one. Despite this, more than one-third of the sample believed that only those who can carry out these healthcare tasks deserve to be labelled 'Home Nurses'.

The next chapter deliberates on relationship building in the caregiving process and other themes related to the stakeholders' interaction.

Chapter 5

When Caregivers and Care Receivers Interact: Relationships, Tensions and Challenges

5.1 Introduction

This chapter explores the partnerships formed by caregivers and care receivers as they interact in the caregiving process. The nature of relationships the caregivers had with the patients and family members they have worked with has been explored. The most and least liked aspects of the relationships as cited by the caregivers have been analysed. The noteworthy incidents in the careers of some of them have been captured. Similarly, the experiences and the kind of interactions the care recipients had with the caregivers are explained. The most beneficial aspects and the disadvantages of hiring a care provider have been examined. The chapter attempts to identify which models of care are prevalent out of the five models presented in the introductory chapter. The analysis has been done from the perspectives of the caregivers as well as the care recipients. The task segregation that exists between formal and informal caregivers has been explored. The chapter also discusses the tensions and challenges both parties face in the association.

The conceptual definitions of some of the terms used in this chapter have to be explained. The term ‘client’ (shortened form of home care client) is used to refer to the patient or the family that avails the caregiving services. The patients’ families are addressed as the clients’ families or informal caregivers. The term ‘employer’ has also been used occasionally to refer to the client or their family. Since only a handful of patients were a part of the study, the patients’ relatives

responded in most cases. These respondents were either the primary informal caregivers of the patient or the heads of the families. The former mostly included the patient's female relatives, whereas male relatives who had a fair idea of the caregiving process and the contract made up the latter. As per the literature on paid caregiving, the patient's family members are perceived as indirect receivers of care since the services are of indirect help to them.

5.2 The Caregiving Relationships: Caregivers' Perspective

The kind of associations the caregivers had with various clients differed. While they maintained close and family-like associations with some of their clients, relationships with some others were formal. When the care providers' overall impression about the clients they served hitherto is considered, more than three-fourths of the sample rated their relations with some of their clients as good and cordial. About one-fifth of the HNs were found to have cordial relations with all the patients they took care of. The remaining caregivers maintained formal relationships with all their clients. Either they wanted to be detached, or the clients decided to keep them at a distance. The numbers reveal that the majority of the caregivers had developed good bonds and were attached to some or all of their clients.

A care provider named *Thilothama* was found to have had good relations with all her prior clients, and one of them had gifted her a refrigerator as they were greatly pleased with her services. She holds the opinion that compatibility is the driving force for rendering commendable services. A male care provider named *Vijay* believes that once an emotional bond develops with a patient, they would treat the caregiver no lesser than a kin member. He recollects an incident of a 49-year-old patient who suffered memory loss. He took care of the patient for a couple of years, and the patient's condition improved with time. The patient got along really well with him and gifted him

a cow (besides paying some cash) at the end of the contract. *Vijay* feels happy that he is still in contact with this client. A few other HNs have had similar instances of clients paying them extra money, gifting them new clothes and objects such as a television or refrigerator when the contract terminated.

As discussed in the previous chapter, the duration of a contract depends on the agency's norms. However, some agencies allowed the clients to have a specific caregiver as long as they wished. This proves that the rapport between the HN and the client/ client's family impacts the contract duration. Good relationships will lead to the clients consulting the agency to allot the same HN whenever they or their relatives need home nursing services in the future. However, some HNs were found to be uninterested in working with the same client for more than a couple of months. Though they understand that they may get closer to the clients with time, it is believed that issues may also arise among both parties as familiarity increases. A few caregivers, who earlier mentioned that the difficulty of the work also depends on the nature of associations with the clients, revealed that bitter relationships would result in the caregivers dealing with an excessive workload. The clients' families neither give them enough time for rest nor appreciate them for a work done well.

Commensality or the practice of having food together could be a factor that reveals the nature of relations between the two parties involved. In the case of an employer-employee relationship, the practice of letting an employee eat at the same table can help one understand the way the employer treats the employee. It might also reveal if the employee is comfortable with the employer. While one-third of the sample did not dine with their employers in any of the homes they worked, close to half seemed to dine with some of their employers. 18.67% stated that they had dined together with all their previous clients' families and recalled how eating together helped

develop a sense of belonging in them. They appreciated this gesture and felt content that the employers considered them like family despite being strangers. It was also informed that several clients wanted to maintain mutually respectful relationships and thus, were concerned about dignified and egalitarian treatment to the caregivers. Some of the HNs mentioned that they usually ate alone, but on special days, such as festive occasions, the clients had food together with them.

The reasons for not dining together disclose that the greatest number of HNs (42.67%) cared for patients who required assistance with eating. These caregivers fed the patient first and had food only after ensuring that the patient's requirements were met. For around 12% of caregivers, the food timings differed from the client's family. They used to eat after everyone else finished their food. The remaining people believed that sharing dining space with employers is not etiquette. Though some of them were asked by their clients to dine together, they refused. This is especially the case with female caregivers since they did not want to sit alongside male relatives of the clients. So, they used to eat with the female members separately or sit in the kitchen and eat alone. A couple of caregivers were seen to be clinging to the idea of power dynamics, and they considered employees interacting freely or being at close quarters with the employers as an undesirable act. They assumed that work contracts should be formal, and over-attachment could lead to exploitation by employers in different ways. A group of HNs did not dine together with the clients' families since they believed that the family members needed privacy. In the presence of an outsider, they would not be able to discuss their family matters which they otherwise do during their dining hours.

It is worth noting that a handful of caregivers believed the clients' relationships with them are affected by several factors, the major one being their personal characteristics such as caste affiliation, appearance and hygiene. *Vijayamma*, a postnatal care specialist who had good relations

with the clients, has been dining together at all the households she had worked. She states that depending on the individual's caste, physical appearance, and cleanliness, the clients interact with them or come in close contact. Since she belongs to an upper caste and is 'clean-looking', she feels that the clients found her good enough to share the dining space with.

An effort was made to identify if the patients or their family members treated the employees differently with regard to food practices. The findings may throw light on the clients' families' discriminatory nature or their hygienic nature of using separate dining spaces, timings, and utensils. Less than one-fifth of the caregivers were provided with separate plates and glasses, and they used to sit alone in a place like kitchen to have food. More than half of the informants had separate food timings since they first fed the patients and ate later. However, they used to sit alone in the same dining area and have the same utensils that the client's family members used. 11.33% did not have separate food timings or a different dining place but were given separate serving dishes. In the cases of the remaining caregivers, the food time, dining place, and dishes were the same as that of the clients' family members.

5.3 The Linkage Between the Caregiver and the Patient

From the previous chapters, it is understood that the connections they build with the patients is one of the aspects the caregivers value the most about their jobs. Several HNs had highlighted the significance of spending quality time with the patients and developing friendly relations. Some care providers have revealed that their constant presence in the patient's room has some obvious benefits. Staying in the same room as the patient not only helps them monitor the patient's health condition and attend to their needs in real-time but is also expected to improve the

bonding between the two. With time, the caregiver builds rapport with the patient by sharing stories and incidents about personal life and providing companionship and emotional support when the latter's relatives fail to do so. It was found that the majority of the HNs (85.33%) stayed in the patients' rooms. The remaining caregivers were either provided a different room or did not stay with the patients since they worked part-time. A couple of HNs noted that the place of stay depends on the patient's gender. Out of the 35 woman caregivers who have taken care of male patients, only three have stayed in different rooms. Most women found it comfortable to share the room since the patients were bedridden, too old and frail, or suffering from life-limiting illnesses. Such men did not pose a threat and were often termed 'harmless'. If they faced any unacceptable behaviour from the patient, they could inform the patient's family and sort it out. If the case seriously hindered the caregiver from carrying out their duty, they could report the issue to the agency for a resolution.

Some caregivers hinted at the possibility of patients finding it difficult to share the room with the caregiver, who is a stranger. Owing to this issue and other privacy concerns, some clients allot separate rooms to the caregivers. A few caregivers assumed that the relatives of some bedridden patients could have been apprehensive about what would happen to the patient if left alone with the caregiver. This issue seemed to have occurred in the case of caregivers that are new to the clients but not with those who had worked for a more extended period with the clients and gained their trust. A caregiver named *Asha* notes, "In this case, we cannot blame the patient's family for not trusting us. There have been instances of theft. Two years back, I heard the news of a home nurse stealing gold from a client's house". She added that such people are a shame to the entire community of home nurses.

Several caregivers reported their patients treating them like family, and some of them proudly mentioned that there had been elderly clients who were closer to them than to their children. Some HNs recalled their patients who remained in touch even after their contracts ended and expressed their desire to meet them when they were in the final days of their lives. 28.67% HNs opined that the elderly patients treated them like their children/relatives. Almost half of the respondents (49.33%) had the patients behave friendly with them. While 20.67% HNs had formal employer-employee relations, a meagre 1.33% had bitter relations with the patient they took care of. These patients had an arrogant nature and were stubborn that they refused to co-operate with the HN in the caregiving process.

A respondent named *Sulochana* opines that one has to love the patients no matter what. She adds that half of their illness will get cured if they feel that they are getting love, care, and attention. However, this has not been the opinion of some other caregivers, and Binoy is one of them. He voices that he had a few bad experiences with his clients and families. Sometimes, some patients have unexpectedly behaved violently, beat him up, and shouted at him unnecessarily. Some of the patients' family members have hurt him by not treating him with respect and dignity. He had been asked to sit outside the home and have food, not sit near the family members to watch television, and avoid using a mobile phone. Binoy expresses his grief states that he treats the clients and families like kin and expects them to consider him like one. He adds, "sometimes I feel that I am not truly recognised or respected for the job I perform".

The caregivers' perceptions on taking care of unfamiliar clients were analysed. It seemed difficult for the HNs to take care of strangers since they did not know those families or how they would treat them. Several HNs, especially women, have expressed worries such as the fear of staying in unknown people's homes, getting along with them and their families, or taking care of

patients of the opposite gender. Despite this fear and apprehension that they had initially had, several HNs were ready to take up any contract and see how the situation turned out for them. The majority of the caregivers (61.33%) did not have a problem attending to strangers because they consider it part of their job to serve whoever employs them. 24.67% opine that they consider the patient as a human being who needs care and, therefore, are okay working for any patient irrespective of the relation with them. The remaining wanted to consider the patients like their kin and take good care of them. However, a few caregivers conveyed their apprehensions about getting attached to the patients as it may later have different negative consequences. Some of them liked the interpersonal relationships to be formal though they work in an informal setting like home.

Seven HNs left their jobs as staff nurses as they were unhappy with their salaries, work conditions like night shifts, and how the hospitals were organised. These nurses perceived the relationships with patients in home-based care to be different from a hospital setup. They found themselves better able to take care of the patients since they spent more time with them. When they have to attend to many patients at the hospital, the nurses hardly find time to speak to the patients or show them enough care and concern. Now that their schedules are not tight and since they can focus on a single patient, they get enough time to do whatever the patient wants them to. In the words of one of the informants, “when you are into home-based care, you spend all the day with the patient, and this helps build a strong bond”. Compared to hospital-based care, all seven nurses found that home-based care offers them more autonomy. They do not have much command in a hospital setup as they are lower in the organisational hierarchy. They have to follow the rules and regulations of the organisation and treat the patients accordingly. Contrarily, in home-based care, they seemed to be at ease as there is more flexibility. It was observed that being nursing-educated, these HNs had a say in healthcare matters of the patients, and the patients’ relatives

valued their opinions. However, since they stayed in the clients' homes, they felt that they had to be more cautious and watchful.

To understand the patients' families' involvement in the caregiving process, the HNs' opinions were sought on if they thought the extent of participation was adequate. Almost one-fourth of the sample agreed that their family members looked after the patients very well. One-third of the HNs felt that the clients' families showed moderate care. Less than one-fifth supposed that the care given to the patients by their kin was poor since they did not co-reside with the patients. About a quarter of the informants expressed their concern. They opined that the clients' kin considers caregiving the HNs' duty and thus do not involve in the caregiving process as much as expected. According to some HNs, adult children do not spend enough time with their elderly parents. Though they spend money for the healthcare of parents, the children should also show affection and care towards their parents despite their busy schedules.

A caregiver named *Thilothama* states: "Some children who consider the care of the patient as the sole responsibility of the paid caregiver should realise that their parents are yearning for their love and care". She believes that one of her elderly clients who had mental illness became sick due to the lack of affection and love from her kin. Another caregiver named *Ajeesh* has a concern about deteriorating family values. He expresses his grief that their families did not properly treat some of the patients he had cared for. He remarks, "when parents age, some adult children feel that they are a liability. I have seen people who refuse to touch their bedridden parents and speak to them with love. It pains to see such cases where blood relations are not given the value they deserve". Nevertheless, *Ajeesh* feels content that he has given good care to a few elderly patients in the final days of their lives.

5.4 The Caregiver and the Client's Family

When it comes to the caregivers' closeness with the patients' relatives, 18% of the sample seemed to have had very close and friendly relations with all their clients' families. About two-thirds of them felt that they and their clients' relatives were fairly close and had a moderate level of interaction. However, 10% opined that they never discussed anything other than work-related matters. These HNs like to maintain formal relationships with the clients' families and try not to involve much in their personal lives. The remaining posited that they were very close with some of their clients. A postnatal caregiver named *Ponnamma* comments that all her clients' families have been very good and treated her with love and care. While at work, she does not miss her kin or have any kind of homesickness since she has disturbing relationships with her family members. She is happy that several of her clients' relatives were kind enough to consider her as a parent figure while her own children made her destitute. She notes, "None of the clients' family members ever referred to me by the term 'Home Nurse'. Everyone calls me '*Amma*' (mother). It could be due to my age. They all respect me and are satisfied with how I take care of the newborn and its mother".

Here is the case of a care provider named *Prasanna Kumari*, who has developed cordial relationships with several clients and families.

Case - 01

Prasanna Kumari is a 66-year old widow with eight years of experience working as a home nurse. After her husband's demise, she started working to keep her life going. She belongs to a higher caste and has a bachelor's degree. Since she did not want to reveal her educational

qualification, initially, she lied that she was a Class 10th failed person. Later she admitted that she did not want to let anyone know that she had chosen domiciliary care work due to her helplessness, despite her good educational background. She views the job as challenging and finds it hard to lift heavy patients and deal with the patients' excrement. None of her relatives, not even her daughter, knows that she works as a home nurse. Since her daughter does not live with her, she has managed to convince her that she stays with one of their distant relatives in another district.

She has had excellent relationships with most of her clients and their families. She has been treated as a family member by many, and she is still in contact with them. Though she might not like the situations at some homes, she tries to adjust to them and remains there till the end of the contract. She does not want to create trouble or quarrel with the clients' families for petty reasons. She believes that minor issues and concerns would be there irrespective of the clients one works with. She proudly states that her understanding nature, decent behaviour, and good communication skills have earned her clients' trust. She adds that nobody has referred to her as a 'home nurse' so far, not even the clients' family while introducing her to their acquaintances. She was always treated like a relative and called 'Amma' (mother) or 'Chechi' (elder sister). She recalled a client's daughter introducing her as their distant relative when a neighbour inquired who she was. Though she does not have a high opinion of the job, she is content about the connections she builds by being in this caregiving sector.

The cases of two caregivers discussed above reveal that not addressed by the term 'home nurse' is considered a sign of closeness with the clients' families. Using terms such as 'Amma' or 'Chechi' shows their acceptance in those families. Almost all the caregivers who cited forming family-like relationships with the patients or their relatives noted the usage of kinship terms.

5.5 Keeping the Bond Alive: Contacts with Previous Clients

Several HNs reported that they maintained connections with some of their earlier clients. One-tenth of the respondents did not have any contact with their previous clients or families. While a negligible 5.33% remained in touch with all their previous clients, the majority (84.67%) had connections with most of the families they earlier worked for. There appeared to be some who stayed in contact to keep track of the patient's health status. In some cases where good rapport was established between both parties, the clients had suggested the same HNs to their friends and relatives who required home nursing services.

A handful of informants stated that staying in touch with previous clients is easy these days since WhatsApp and several social media platforms are available. A caregiver named *Priya* seems to have found happiness in occasionally video calling some of her favourite elderly clients who were like grandparents to her. Though she is at a distance, technology has made it possible to meet her favourite clients virtually. She acknowledges that these conversations help her cherish the good times she spent with them, and seeing the clients' smiling faces is pure joy. She adds, "There is no bigger happiness than finding that I have made a change in these patients' lives and learning that they are grateful to the services I provided".

Table 5.1: Caregivers' relationships with care receivers (n=150)

Sl. No	Characteristic	Numbers and Percentages (in parentheses)
1.	Caregiver's relationship with the existing client	
	Very good, the patient treats the HN like own child/ kin	43 (28.67)
	Good, the patient behaves friendly	74 (49.33)
	The patient treats the HN just like a caregiver	31 (20.67)
	The patient does not like the HN	2 (1.33)
2.	Caregiver's relationship with the client's family	
	All were very close and friendly	27 (18)
	Some were very close	10 (6.67)
	Moderate interaction with everyone	98 (65.33)
	All formal. Did not discuss anything other than the patient's health	15 (10)
3.	Caregiver's opinion on the clients so far	
	All were good and cordial	26 (17.33)
	Some were good and cordial	114 (76)
	All were formal and detached	10 (6.67)

4.	Caregiver's contact with previous clients	
	In contact with all clients	8 (5.33)
	In contact with some clients	127 (84.67)
	Not in contact with anyone	15 (10)

5.6 The Patient and the Care Provider: The Care Receivers' Perspective

Cordial relationships and cooperation between the patient and the care provider contribute to an effective caregiving process. The perspective of the caregivers has been presented above. The care recipients were inquired of the rapport between both parties to understand if the patients mingled well with their caregivers. On a scale of 1 to 5 (1 being very poor and 5 being very good), about two-thirds of the respondents felt that the quality of the relationship was very good or good. Most of the clients who gave a moderate rating stated that the relationship does not remain the same throughout the contract, and there could be times of good rapport as well as times of bitterness. Less than 10% of the informants held the view that the relationship was poor as the patient could not get along well with the care provider. When it comes to the co-operation between the two, a little over half of the sample found that the patient was very co-operative. Almost 45% rated the patient's co-operation in the caregiving process as neutral.

Leaving the patient with the care provider, to an extent, implies the level of trust the clients have in the care providers and the good relations that exist between the two parties. The highest number of informants were seen leaving the patient daily with the care provider whenever they could not be present at the residence. This includes cases where the relatives of the patients stay

in a separate household and cases where the relatives go outside daily for work. Most of the remaining respondents also stated that they were fine with the care provider being with the patient in their absence. Only two people stated that they do not like it that way and try to be with the patient always, except during unavoidable circumstances. *Riya*, one of the two respondents, recalled an incident that made headlines a few years ago. A home nurse who took care of an elderly couple stole some gold and rupees one lakh cash. This was discovered much later by the clients' relatives since they do not visit the elderly couple regularly. However, the culprit was arrested by the police. *Riya* added that such caregivers are a nightmare since one cannot predict their intentions or guarantee the safety of frail elderly patients. In general, the clients' families wanted to ensure that the caregiver was well-mannered, trustworthy, and genuinely interested in looking after the patient. Once they are convinced, they would not have many worries about the caregiver's character or the patient's safety in their absence. However, this does not happen in the case of clients who require the services for a short term since they cannot wait to form a fair idea of the caregiver's nature.

Here is the case of a patient who availed of home care services for post-surgery care.

Case - 02

Beena, a teacher by profession, is a childless widow. She had employed a caregiver for three months while bed rest was prescribed after a hysterectomy. The caregiver, who was elder to her, took care of her like how a mother cares for a daughter. Beena's mother is not alive, but the caregiver did not make the absence felt. She was the one who stayed with her as the bystander in the hospital at the time of her surgery. Once they were discharged from the hospital, Beena did not seek any of her relatives' help as she found out from the nursing agency that the caregiver was a trustworthy person. Beena was pleased with the caregiver's services and developed a good bond

with her. It was very difficult for the home nurse to end the contract and leave. She still stays in touch with this caregiver and meets her occasionally. She recalls that the caregiver invited her to attend her granddaughter's wedding. The caregiver has promised Beena to help her whenever she requires some assistance. She thinks that the absence of family members or relatives in the house could be a reason why the caregiver became so attached to her in a short period. Had there been others, the caregiver would have involved lesser in Beena's daily activities and spent less time for casual conversations. She feels happy that the caregiver was not overburdened with tasks. She used to instruct the caregiver to have enough rest and leisure. In Beena's view, caregivers should be treated fairly by their employers. She remarks, "The ones who mistreat these caregivers should realise that they are obliged to provide the latter with decent work conditions". She laments, "Since you hire them does not mean that you have to make them work endlessly".

Discussed below is the experience of another woman who employed a caregiver after her surgery.

Case - 03

Bindhu is a 48-year-old lady who underwent a hysterectomy in the year 2018. She works for a private company based in Thiruvananthapuram. She is a divorcee who has a daughter studying abroad. She resides alone, but her elderly father visits her occasionally. Since she does not have any female relatives, she had to seek the help of a caregiver during her hospital stay and for a month post the surgery. Bindhu was assigned a carer aged above 60 years. She was healthy and had the knack to deal with post-operative care. She used to cook food besides supporting the patient in her daily activities. There was no need to do any household chores as a maid would come daily. In a few days, the HN built an excellent rapport with her. The two of them stayed in the same room, and the HN was ready to help whenever Bindhu needed some assistance. She was

really content with the caregiver's tidiness and hygiene. She recalled an instance where the HN brought her some home-cooked food and sweets when she visited her family. Bindhu expressed her satisfaction with the HN's services and stated that the latter helped her recuperate faster and better. Bindhu holds the view that the care provided by home nurses is a boon to patients who do not have adequate family support.

5.7 Clients' Families and their Relations with the Care Providers

During their stay at the workplace, the caregivers frequently interact with the client's kin who co-reside. On many occasions, they help the caregivers when they require some assistance with the caregiving tasks. The caregivers' comments on their relationships with the patients' families have already been noted. Upon exploring the perceptions of the clients' families, it was identified that close to 90% of the respondents wanted the caregiver to behave with them like a member of the family. Nevertheless, the care providers' responses on how their clients' families treated them do not seem to agree with this. As per one-third of the clients' relatives, the home nurses closely interacted with them. The greatest number of informants declared that the relations were close. A good number of people reported that the interactions were neither too friendly nor too formal. Only eight clients' relatives found the care providers to distance themselves and not share any personal matters.

From the information given by the care providers, it could be understood that those clients who let them have food together and do not discriminate against them are considered friendly and approachable. As per what the clients' families reported, less than one-fifth of them had food daily with the care providers. While about a quarter dined with the caregivers on some special occasions,

more than half of the clients' families never followed the practice of commensality. One of the reasons for not dining together as provided by the clients' families is that the caregivers had different food timings. Some clients' kin avoided eating with the caregivers owing to the idea that employees should not be given much freedom. The remaining seemed to have insisted the caregivers dine together, but the latter refused.

Some clients' relatives expressed that their responsibilities were significantly reduced after hiring the caregiver. In several cases, the caregivers took up the role of the client's primary caregiver. Presented below is the account of a formally employed woman whose family had to depend on a home nurse for her mother-in-law's care.

Case - 04

Ajitha worked as an office staff in a college. Her husband was employed in the state police department and had to be away from home at times. The family had to seek the help of a formal caregiver due to the work-related matters which kept them busy. They seem to have had a good experience with the caregiver and was satisfied with her service. Ajitha comments, "The home nurse was very caring to our mother, and she worked as per the instructions we gave her. She was a well-mannered woman who did her best to take care of the patient's personal care tasks, and we treated her like a family member. She helped the patient cope with the situation, but her efforts were in vain as our mother passed away in a few weeks". Though she was not a professional, the lady ensured that the patient's catheter care, sponge bath, bedsore care, etc., were done properly and hygienically. The HN was paid one month's salary although she worked only for a fortnight. She was with the family until the funeral functions of the patient were over. Ajitha mentions that

the HN remains in contact with them even now. She does not have any complaints or bad remarks on the caregiver since the lady was well-behaved and co-operative. She is grateful to the caregiver for her efforts and sincerity and adds that it would have been a burden for her had they not employed the care provider. The couple feels that domiciliary nursing services are a helping hand to nuclear families where both adults are employed, and when their relatives are not ready to take the responsibility of the sick person.

Plate 5.1: A client and their caregiver



Source: Fieldwork

5.8 Long-term Relationships with the Caregivers

Though the contracts with their care providers ended formally, some of the clients' relatives stayed in touch with them for various reasons. While some maintained the relationships casually, a few others were in contact since they wanted the home nurses to work for them whenever they would have a requirement in the future. As stated above, a couple of clients who were satisfied with the services referred the care provider to some of their relatives/ neighbours. While almost half of the respondents maintained contact with all the home nurses who worked for them, a few were reported to be in touch with some nurses. More than one-third of the sample stopped contacting the care providers once their contracts ceased. Acts such as the clients retaining connections with the care providers through phone calls or occasional meetings and helping them find employment by making referrals reveal that there exist friendly relations among both.

About a quarter of the clients' families invited the caregivers during gatherings on special occasions such as wedding celebrations or funeral ceremonies of the patients they had taken care of. Upon analysing the reasons for inviting the caregivers to the functions, half of the respondents casually welcomed them like any other guest. In contrast, the other half wanted the home nurses to help them prepare for the functions. The latter paid the home nurses for the number of days they worked. A couple of informants informed gifting new clothes to the caregivers. One of them stated that some people are ready to offer housekeeping support. She added, "The caregivers might not be employed throughout the year. So, if we are providing them with some work and letting them earn when they do not work anywhere else, we are doing something beneficial to them."

Table 5.2: Care receivers' relationships with caregivers (n=76)

Sl. No	Characteristic	Numbers and Percentages (in parentheses)
1.	The rapport between the patient and their caregiver	
	Very good	19 (25)
	Good	30 (39.47)
	Moderate	20 (2.32)
	Poor	7 (9.21)
	Very poor	0 (0)
2.	Client's family's relationship with the caregiver	
	Close and friendly	37 (48.8)
	Moderate closeness	31 (40.79)
	Formal and detached	8 (10.53)
3.	Patient's co-operation in the caregiving process	
	Very co-operative	40 (52.63)
	Neutral	34 (44.74)
	Not co-operative	2 (2.63)
4.	Client's family's contact with previous caregivers	
	In contact with all caregivers	37 (48.68)
	In contact with some caregivers	8 (10.53)
	Not in contact with anyone	29 (38.16)
	N.A. since the contract is continuing	2 (2.63)

5.9 Task Segregation: Perceptions of Caregivers and Care Receivers

As they enter into a contract, the caregivers involve in several duties at the clients' homes. Some of these duties would be fully transferred to them from the clients' informal caregivers, while both would share some duties. To understand this task segregation, the nature of duties they performed by the caregivers was explored. Only one-fifth of them seemed to have attended to the patients' care exclusively throughout their careers. The remaining have provided housekeeping support besides patient care in many of their contracts so far. Ten HNs out of this category volunteered to help with household chores though their employers had not instructed them. It was observed that most of the male caregivers helped the clients' families in tasks such as grocery shopping, running errands, driving the patient to the hospital, etc. Except for two people, none of the men had to involve in chores in the kitchen. These two men had to cook for the patients as their relatives did not reside in the same household.

On the other hand, about 60% of the clients seemed to have employed the caregivers to exclusively take care of the patient's health and personal care needs. The remaining informed to have received the home nurses' help with some of the household chores in addition to caregiving tasks. However, out of these 29 respondents, eight reported that the caregivers willingly undertook the housekeeping tasks and shared their responsibilities. The caregivers reported similar instances, which have been included in Chapter 3. All of these care providers are women who did not want to sit idle during their free time. They liked to help the patients' female relatives and did not find it overburdening. Instead, they felt that it was their courtesy to help the womenfolk. None of the clients reported denying their caregivers entry to the kitchen even if they belonged to lower caste backgrounds or looked less clean. Nevertheless, a handful of caregivers informed of the clients'

relatives not letting them do any work in the kitchen and suspected it could be due to the caste affiliations.

5.10 Caregiving Partnerships: Which Model of Support Prevails?

The theoretical framework employed in this research (presented in Chapter 2) discusses the caregiving networks formed by the informal and formal caregivers, their partnerships in the process, and the different models of support they result in. An attempt was made to identify the models that are dominant in the study area. Since the sample sizes of the two categories are varied and the caregivers were not associated with the same set of clients, the models are analysed separately from the perspectives of care recipients and caregivers. The terms ‘support’ and ‘help’ refer to the direct assistance provided by the informal caregivers to the formal caregivers to enable the latter to perform activities aimed at sustaining or improving the patient’s health condition. Indirect help in the form of assistance with Instrumental Activities of Daily Living (IADL) such as managing the finances or transportation was not considered.

When it comes to the case of caregivers, there has been a difficulty in categorising since each caregiver has attended to several clients throughout their careers, and the circumstances have not been the same with every case. Therefore, the caregivers were required to explain the type of caregiving associations with most of their clients’ families. Two-fifths of the respondents reported that most of their clients’ relatives assumed the home nurse to handle the caregiving singlehandedly. It was found that only one-third were supported by most of the patients’ relatives to perform the caregiving tasks. Some families were reported to be providing housekeeping support but not helping with the patients’ care. One-fifth of the HNs testified majorly being in such

relationships where they and the clients' relatives carried out different tasks in the caregiving process. In the majority of their assignments, seven caregivers seemed to have worked for elderly clients who did not have any co-residing relatives, thereby bearing the entire caregiving responsibility.

In the case of care recipients, almost two-thirds informed not delivering any support to the caregivers. The relatives of six patients were seen to have actively partnered with the caregivers in performing the caregiving tasks. In fact, they seemed to have performed a more significant part of the tasks while the HNs assisted them. More than half of the respondents carried out tasks different from the HNs. Only one of the cared-for persons entirely depended on the HN as she did not have any family members present.

The greatest number (41.33%) was involved in a substitution model from the home nurses' standpoint. The patients' families withdrew from the caregiving process as the HNs started working in these cases. This model was followed by a supplementary model of support that was prevalent in one-third of the cases. These HNs reported assisting the clients' relatives who played the role of the clients' primary caregivers. Task specificity model was observed in about one-fifth of the cases. A compensatory model of support was identified by less than 5% of the sample.

From the perspective of the care receivers, the most prevalent model is task specificity which was reported in over 60% of the cases, and there existed a clear division of labour between the HNs and the formal caregivers. While they attended to the household chores, the home nurses were exclusively assigned the patient's care. More than a quarter of the sample provided evidence for a task-specific model. The families did not take part in the patients' care post the arrival of the HN. In a few such cases, the caregivers performed patients' care and assisted the patients' relatives in the household chores. The next prevalent model is supplementation, where the patients' relatives

actively participated in the caregiving process, and the home nurses' efforts supplemented them. There was a single case in support of the compensatory model. The results confirm that the patients' families contributed to the caregiving process to some degree in almost all the cases.

Figure 5.1: Models of care from the caregivers' perspective

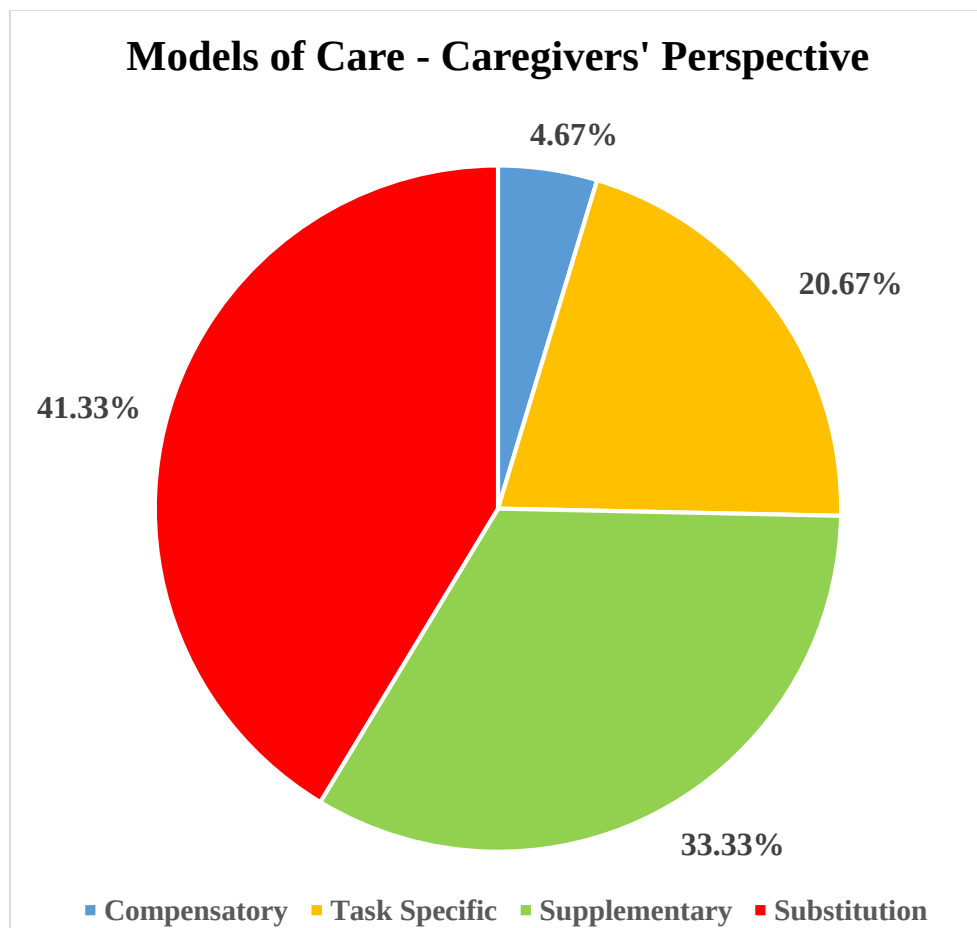
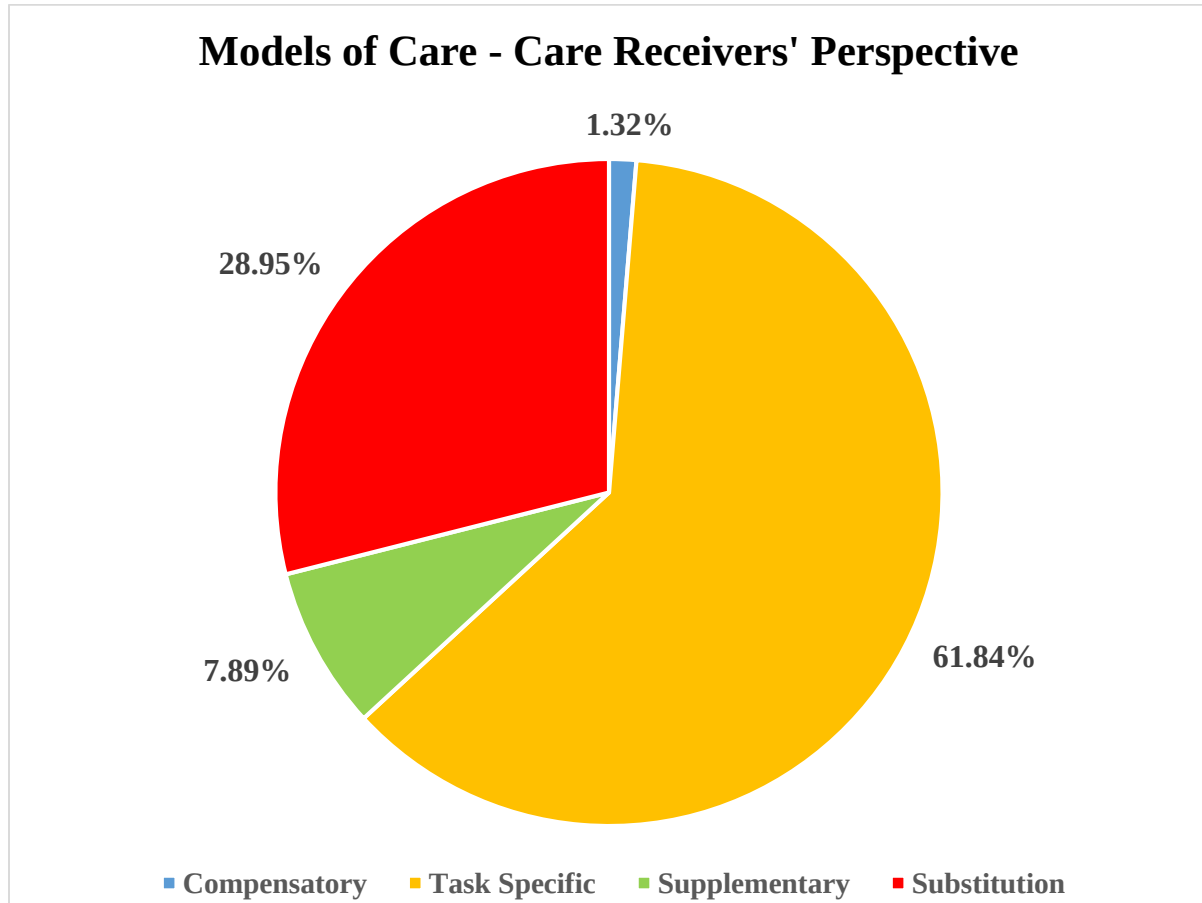


Figure 5.2: Models of care from the care receivers' perspective



5.11 Home Care Agencies- The Mediators in the Industry

As they play the role of mediators in the home care industry, the agencies have to see that they do their best to avoid conflicts between the care providers and their employers. In case of any issues between the clients and the HNs, the agencies interfere and attempt to resolve the issues in a manner that does not harm either party. To ensure that the system functions smoothly, the agency

managers try to save the caregivers if they are innocent. However, as reported by the agency owners, they do not try to interfere in cases where they find the home nurses guilty. Also, there have been a few instances where the agency could not sort out the issues and thus had to seek the help of the police.

In order to make their expectations on the caregiving associations clear to the stakeholders and regulate the nature of relationships, the agencies have framed separate instructions for their employees and customers. Some of these have been elaborated on in Chapter 4. The agency wants both parties to treat each other with respect and dignity. Up to an extent, all the agency owners who took part in the study seemed to be satisfied with the relationships between their staff and the customers. It was revealed that several clients offer gifts to their caregivers as a token of love and appreciation even though the practice is against the agencies' conditions. As per an agency owner, some HNs (especially those who have had long associations that took excellent care of the patient or played a vital role in the patient's recovery) have benefitted monetarily. He cited instances where customers gifted their HNs in kind like gold, clothes or cattle besides their regular payment. Some have been paid as much as one lakh rupees at the end of contracts that lasted for years. There have also been cases where customers supported their HNs by contributing to home construction, taking care of children's education and offering financial support for their marriage.

Though such cases of good bonding prevail, the agency owners feel that a lot of things go wrong in many associations. There have been instances of undesirable behaviour from the employers' part as well as the employees' side. Several agency owners somehow think that it is difficult to take one party's side when a problem occurs between the two. However, the majority reported they would do their best to support the home nurses who they think are sincere and committed to the job. This is decided based on their feedback from the previous clients for whom

the HNs worked. The agency will not blame the HNs or terminate their employment if they are innocent. Nevertheless, in cases of those HNs who have suspicious behaviour or a previous history of creating some trouble at the clients' homes, the agencies do not try to defend them. If the issue is severe, they leave it to the police or law. In a few instances, some managers have spoken to their clients and requested them to treat the HNs better. A couple of agency owners drew attention to the difficulties faced by the employees due to the harsh and inhumane treatment by some clients. Listed below are some of the major issues as perceived by the agency owners, which they like to see changed.

- The excessive workload does not allow home nurses to rest and sleep properly. The problem is mainly faced by those caregivers who also help their clients with household chores. Some clients keep giving the HNs some work or the other if the latter is seen sitting idle.
- A few female HNs suffered cases of misbehaviour from some male patients or the male relatives of patients. A handful of HNs seems to have reported to the agency managers that they have difficulty sleeping properly at night times due to the fear of being prone to harassment. The agencies have always ended the contracts of the HNs with such clients that pose a threat to the HNs' safety. They also instructed them to be extra careful and watchful and promptly report the further occurrence of such incidents.
- The difficulties related to discriminating food practices and the clients' act of not feeding the HNs properly. Several HNs have brought issues such as being made to dine on the floor or in the kitchen, served food in different utensils, and not given special foods like non-vegetarian items, etc., to the agency owners' notice.

- Some caregivers have complained that they are not provided with a good and comfortable place to sleep. A few of them were made to sleep on the floor, and some were not given mattresses by their clients.
- Though the clients are instructed to let the caregivers use the same washrooms as the patients, a few did not follow it. Some HNs had to use washrooms that were not attached to the rooms but built outside the house. This becomes difficult, especially for the female HNs who have to use the outside toilets even at night.

5.12 Issues and Challenges in Caregiving: The Caregivers' Standpoint

Any care provider could have faced different challenges and gone through difficult situations as they work with varied clients throughout their careers. There could be problems that are clearly due to the fault of the customers, while some others could arise due to misunderstanding or troubles that both parties have in getting along. In Chapter 3, it was discussed that abusive relationships with clients and their families, difficult work conditions, work overload, and inconsiderate behaviour of some patients were the aspects that made the caregivers' jobs less interesting. Though the external problems are there, the caregivers were required to list out the health issues (physical or mental) that anytime restricted them from performing their jobs to the best of their capacities.

The health issues faced by caregivers of patients suffering from chronic illnesses have been the subject of much research to date. While a section of the caregivers reported that they were healthy, close to two-thirds of the caregivers in the present study suffered from some health issues (though the severity of the illnesses differed). A good number of people (27.33%) had minor

weaknesses such as body aches. This was either due to their age or their physically demanding work. A relatively lesser percentage of respondents had diseases like B.P, cholesterol, and diabetes, whereas 9.33% treated cardiac and pulmonary-related diseases. One of the caregivers stated that she feels depressed at times, and one other had some disability that limited her ability to do heavy physical labour. This disabled caregiver has a hunchback and finds it a bit difficult to walk. She took up the role of a live-in care provider as it requires money to keep her life going. Her husband died of lung cancer, and she is childless. She feels that the job has given her income and some good clients who treat her like family.

As far as the emotional issues faced by the caregivers are concerned, more than half of them did not seem to have gone through bouts of depression or any kind of sorrow, loneliness, or lack of freedom while working with their clients. The remaining HNs reported experiencing some of these difficulties. Out of the ones who suffered the problems, the majority complained about the stressful and monotonous work life and the loneliness they face due to not having any co-workers or friends with them. Upon analysing the downsides of staying apart from their families, it was observed that half the informants did not face any difficulties. More than a quarter found it hard to be distant from their children. Most of these people had young children who were unmarried/ school-going. A few caregivers were worried about the illnesses of their family members and other issues in their families. A meagre 5.33% did not have any kind of homesickness or family-related worries since they did not have any kin members. Also, there were no similar concerns for 10% of the respondents who were undertaking a part-time job.

Several caregivers had reported that their families were unsupportive of their occupational choices. Some of them had kept their jobs a secret from their relatives, and the issue has been

elaborated in Chapter 3. The female care providers' families' (mainly, spouses or parents) reactions to them taking care of patients of the opposite gender were looked at. About 23% of them had taken care of male patients so far. Two-thirds of this category found their families support their decision since they are paid around 2000 rupees extra when caring for male patients. Six informants cited that their families were fine with their work, irrespective of the gender of the patient they treated. A handful of caregivers kept serving male patients as a secret from their family members. These HNs were sure that their families would react badly if they knew that they were taking care of men. The remaining women informed that they have no concern as they do not have families.

It has already been discussed that a good number of caregivers provide their clients with housekeeping support as well. Involvement in different tasks can result in a stressful routine. For instance, if the patient's care is more demanding, it would become tough for the caregiver to carry out other tasks, including the IADL of the patients. It was thus decided to identify if the HNs were overburdened due to caregiving. More than 85% found the work conditions unobjectionable. However, the remaining felt that the caregiving process was stressful. A couple of HNs informed that they were assigned more tasks and thus, had to go the extra mile to guarantee that they carried out their duties properly.

5.13 Unpleasant Experiences with the Clients and their Families

It has already been discussed that some caregivers did not have very good relations with their clients. About one-fourth of the HNs was not satisfied with the way their clients or their families treated them. These care providers felt that they were not respected for their work and

were treated like maids. Some respondents opined that every person needs to be treated in a dignified manner irrespective of the work they perform. A few HNs pointed out that some clients' families did not provide them with essential material needed for patients' care (such as gloves, masks, and diapers) but expected them to deal with the patients' excrement in an unhygienic way. Some others expressed their disappointment over the unhygienic conditions in some homes. One of the caregivers had a client who raised around ten cats. The cats often used to soil the client's room, and the caregiver had to clean up the mess every time. The HN remembers that it almost became her duty since the client's family never dealt with it. A male care provider named *Joy* had an experience of ill-treatment by a patient's family members. He was made to eat food in a separate place near a dog shed in the home. He adds that though such bad experiences have been there, most clients have been friendly and behaved well with him. Another male caregiver, *Ajeesh*, had gone through the issue of being falsely accused of theft. He was indicted for stealing a gold chain that went missing. When interrogated by the police, he was found innocent. Though he could prove his innocence, *Ajeesh* was deeply hurt when the client's family suspected him. Barring this, he did not experience any other instances of ill-treatment from the clients or families. Several other respondents opined that the clients' families could not be blamed for suspecting the caregivers who are strangers to them. They added that they would not mind if the employers checked their bags and belongings before leaving at the end of the contract.

It has already been discussed in the previous chapters that a section of clients like to hire caregivers who belong to their own communities. Several others were not particular about the caregiver's caste affiliation; instead, they looked for people compatible with their culture. While discussing this aspect of cultural compatibility, a Christian client remarked that they had a Hindu caregiver who learnt Catholic prayers and read Bible verses for the elderly patient. The client also

added that they treated the HN as one among them though she belonged to another community. When it comes to the differential treatment experienced by the HNs at the workplaces, more than three-fourths of the informants found their clients/ families inquiring about their castes. Some caregivers who worked with Muslim families revealed that they prefer people who share similar beliefs. The others believed that the clients were either not eager to know their castes or did not inquire as their religious affiliations were explicit from their names and appearance. A few Muslim and Christian caregivers laughingly stated that their names or way of dressing (Burkha or headscarf) revealed their religious identities. *Saleena*, a Muslim HN, remarks that some customers did not initially like her since they perceive Muslims as unapproachable and unclean. However, a few of them got along well with her after a period. A respondent named *Sudharma* stated that the majority of the clients call the agency and enquires if they can get someone from their own caste. She added that several clients are bothered about the individual's cleanliness and physical appearance more than their character. She remarked, "They want people who look clean and maintain hygiene. Despite providing good services, some consider people from certain lower castes as dirty and thus try to avoid such people".

Though most of their clients inquired the HNs about their caste backgrounds, less than one-tenth seemed to have suffered some kind of discriminatory practice. Since they belonged to lower caste backgrounds, they were treated differently (served food in different utensils and not allowed to use the dining table or common washrooms and toilets inside the house). Some elaborated instances of clients asking them to sleep on the floor, instructing to sit in the kitchen/ on the floor to have food, or denying some special food items. Most of the HNs who had such bad experiences stated that clients from certain higher castes like *Nairs*, who have a superiority complex behaved

rudely. Less than one-fifth of the informants revealed that they faced issues such as being humiliated in the name of their castes while they were blamed for not maintaining proper hygiene.

Some of the respondents also mentioned instances where their clients refused to be in close contact with them or touch them since they were involved in cleaning tasks. A care provider recalled an incident where she was ill-treated by a patient's relative. She questioned them, "Do I have leprosy? Why do you avoid me? I have come here to take care of one of your family members". A few care providers like her have raised their voices when they felt discriminated against by caste. Another HN reacted to a client's daughter who seemed to speak low of the caregivers' backgrounds. She expressed her anguish, "Those who cannot take care of their elderly parents are worried about the caste of caregivers. What a pity! You want us to clean the patient's urine and excrement, then why bother about our caste?". Another respondent felt that she was not mistreated in the name of caste but in the name of the work she does. Once a client's relative used the term '*ketta vargam*' (which translates as 'awful category/class') to refer to care providers.

It could also be known that to avoid caste-related discrimination, some HNs had disguised their caste and informed they belonged to the same caste of the client or are an upper caste. This has been explained in the chapter on caregivers, and some agency owners confirmed the same. It was found that a few HNs who belonged to the Nair community did not have any issues due to their upper-caste status. However, Lakshmi Amma, a Nair woman in her late sixties, considers it shameful to tell others that she is a care provider. She admits that it would be embarrassing if her relatives knew about the job. She adds that she would never take care of male patients. She has so far worked with only Hindu families of the same caste. According to her, taking care of male patients is not something decent women would choose to do. Another Nair woman had not informed her relatives that she works as a care provider. However, some of her relatives came to

know it; they ridiculed her and asked her to quit the job. She is about 70 years old, and her children do not support her financially. She expressed her concerns and questions, “If I quit this job, who will feed me? Who will buy me medicines? I have decided to work until my body supports me. I do not like this job as such, but since it fetches me money, I am bound to work”.

5.14 Harassment at Work: Report Immediately or Suffer Silently?

Upon analysing instances of physical or mental harassment the caregivers encountered at work, it was revealed that about 16% faced harassment of some sort. This included the experiences they had from clients, clients’ family members, or nursing agency staff/ owners. Among the caregivers that faced such trouble, there were five men. Most of them seemed to have experienced these at unexpected times. Some caregivers shared incidents of patients beating them up out of anger. Since these mainly were patients with mental health issues and stubborn elderly patients, the HNs understand that they cannot be blamed for the aggressive behaviour. Priya, a nursing-educated HN, had experienced some bad incidents, such as patients beating her and spitting on her face. Nevertheless, she bears all that as she realizes that the patients do not do these acts intentionally but out of their frustration. She also reported that some male patients have tried to misbehave with her. She opines that some men think home nurses are promiscuous women and try to take advantage of the HNs. She explains, “There could be some care providers who do like that, but they cannot generalise that we all are loose women or expect us to act in a way they want”. Due to unacceptable behaviour of this sort from some clients’ relatives and male patients, she has almost stopped being a live-in home care provider. She has conveyed the difficulties she has faced to the nursing agency, and now she mostly stays along with patients in the hospital as a bystander.

A care provider named *Saleena* states that being a woman in her mid-thirties, it becomes difficult for her to find employment. Clients' families do not often prefer young women due to complexities like this. She warns that it is not always safe for women to stay in strangers' homes. She has experienced an incident where a male member of a client's family tried to misbehave with her at night. Another female care provider states that since she closes the room's door and sleeps before 10 PM, she never had to face any kind of misbehaviour from any male members of the clients' families. She adds that it is mentioned in their agency's rule book that female care providers have to lock their rooms before 10 PM to ensure their protection. According to several HNs, their nursing agencies are committed to the safety of the employees. This is one of the reasons that prompt them to work via an agency. The agency will be contacted whenever there are any issues related to clients.

A few female HNs who have had bad experiences with male patients (verbal and at times physical too), such as bad touch or vulgar comments, reported the same at their respective agencies and withdrew those contracts. Nevertheless, some do not bring it to the agency's notice for various reasons. Some caregivers were aware of such instances happening to their co-workers. At times, they did not seem to have the courage to react to such incidents or report them to the authorities. A few articulate caregivers feel that the safety and security of the employees should be the top priority of any home nursing agency. They pointed out the downsides of working in a sector with no unions or associations protecting workers' rights. They feel that issues like harassment and discriminatory treatment by the employers or problems such as gender-pay disparity and lack of benefits would have been thoughtfully and promptly dealt with had they been unionized.

Explained below is the case of a caregiver who faced offensive behaviour from her client.

Case - 05

Mariakutty, a 65-year-old woman, has about two years of experience as a caregiver. She is a widow who neither has children nor any relatives to take care of her. She has some health issues and looks physically weak. Since she did not want to beg to meet her medical expenses, she decided to work and earn a living. She finds it a bit difficult to perform her current assignment due to the difficulties in the workplace. From the beginning of her caregiving career, she has been working for a male patient aged above 90. This patient, paralysed on one side of the body, is arrogant and does not like Mariakutty. He quarrels with her and beats her at times, but she does not complain to anyone. She silently bears the pain as she does not want to lose the job. On the day of the interview, Mariakutty had come to the nursing agency to collect her salary, with a swollen face. She informed that she was beaten by the patient the previous day and suffered a toothache. She could not resist him or raise her voice against him.

Due to her deteriorating health, many clients do not like to employ her as she cannot assist them in household chores or perform physically demanding work. The current employer had contacted the agency to assign them a healthier person who could help with household tasks. But, Mariakutty somehow convinced them that she would help them in whatever possible ways. She thinks that it is better to adjust and continue with the contract. Since taking care of a male patient fetches her more money, she has been facing this harassment and did not inform the agency owner about the issue.

5.15 Men in a ‘Women’s Job’: Challenges Facing Male Caregivers

The experiences of some of the male HNs have been explained below with the help of a few case studies.

Case - 06

Satish is a 39-year-old who has been an in-home caregiver since 2012. He is unmarried, and his family comprises his parents and a sibling. He has some financial difficulties, started searching for a better-paying job, and ended up becoming a care provider. He is satisfied with the work and finds it easy to perform the duties. His sister works as a staff nurse, and she taught him some healthcare tasks. During his stay as a hospital bystander, he learned how to operate a nebuliser, monitor body temperature, blood pressure and the like. He also worked in an Ayurvedic hospital earlier.

He has kept his work life a secret from most of his relatives. Satish’s case exemplifies that several men are hesitant to inform their relatives and friends about their work identities due to the fear that they might be ridiculed for working in a field that is often perceived as earmarked for women. To ensure that his acquaintances do not know about his work, he takes up contracts in districts far away from his hometown. Satish feels happy to build worthy and long-lasting relationships with many people by being in the job. He mentions, “once we mingle with the clients and adjust with the situations at their homes, we do not feel like going back to our own homes. There have been times when I stayed for five months straight, without taking even a single day off to visit my family”. Satish does not have any dissatisfaction with the work as he loves performing the role of a caregiver and bringing solace to the lives of chronically ill patients.

Case - 07

Suresh, a widower in his mid-forties, has two school-going children. He used to work as a construction labourer but had to leave the job due to respiratory issues. When his ill health made it hard to do strenuous activities, he searched for an easier job and found this. Tending to patients is an activity he has always liked to carry out. One of his friends who works as a home nurse suggested he could contact the agency she works for. He underwent some training for six months, as a result of which he learnt to perform physiotherapy and other healthcare tasks. In his nine years of experience, Suresh never found the work challenging. He enjoys working with different clients and building healthy relationships with the new people he meets. Suresh kept it a secret from all of his relatives and acquaintances that he works as a caregiver. So, he tries to avoid working in areas where he has relatives or friends. Though he likes to work near his home and have an eye on his adolescent children, he cannot do it. Suresh opines that men who work in the home nursing sector find it difficult to convince others and gain the respect they deserve. He has known some male caregivers who have experienced trouble finding marriage alliances as this is a job usually not preferred for men.

Here is the case of a caregiver who has pride in the service he renders but does not want to reveal his job identity to his relatives or friends since the job lacks respect.

Case - 08

Christopher has been a caregiver for over a decade now. His relatives are not informed about his occupational identity for the fear that they would ridicule him. He states, “To deal with

another person's faeces or urine is something demeaning in the eyes of our relatives, in particular, and the society, in general. However, we know the value and greatness of the work we do. Often, the children of the ailing elderly patients hesitate to do this work. So, if we look from that perspective, the job done by an HN is commendable and deserves respect and recognition".

He narrated an incident that he would never forget. He mostly refers to the elderly patients by the terms 'Achan' or 'Appachan', which means 'father'. Once, he was scolded by an arrogant patient who yelled that someone who has come to deal with his excrement should not refer to him as 'Appachan'. Such a comment disheartened Christopher. He feels that even if they do not appreciate their work, people should not discourage in-home care providers. He opines that people like him come to rescue elderly patients who have none to look after them. He adds that one of the patients he served had eight children, but none took care of him in his autumn days as they were busy with their work and family lives.

On the other hand, an elderly male caregiver named Ajay started working in this sector about four years ago. He is an ex-serviceman who earlier worked in different fields post his retirement from the armed forces. He had been a construction worker in Dubai, later became security personnel at a bank in Kerala, and now a caregiver. Though he does this job, this 62-year-old man sometimes works as a marriage broker. To him, the job is more manageable, fetching him around Rs. 18,000 a month. He had received 6-months of physiotherapy training from Mumbai and learnt to perform some of the nursing tasks required to care for bedridden patients. Ajay does not have any shame in providing nursing services though he believes that this is a female-dominated sector. All his relatives are aware of his occupation, and neither of them seems to have a negative opinion of his job.

Table 5.3: Issues faced by the caregivers (n=150)

Sl. No	Characteristic	Numbers and Percentages (in parentheses)
1.	Health issues	
	Caregivers suffering from illnesses	92 (61.33)
	Caregivers who do not have serious ailments	58 (38.67)
2.	Types of illnesses	
	Lifestyle diseases such as diabetes, cholesterol and B.P issues	35 (23.33)
	Cardiovascular or respiratory diseases	14 (9.33)
	Minor bodily weaknesses such as body pains	41 (27.33)
	Mental illnesses such as depression	1 (0.67)
	Disability	1 (0.67)
	No illnesses as such	58 (38.67)
3.	Emotional issues faced by the caregivers	
	Feelings of depression or loneliness, experiencing a taxing routine, lack of freedom	60 (40)
	No issues, perfectly fine with the work conditions	90 (60)
4.	Difficulty in performing tasks other than patient's care	
	Yes	20 (13.33)
	No	99 (66)
	N.A. since only patient care is done	31 (20.67)
5.	Stress due to caregiving	
	Yes, experienced burnout	22 (14.67)
	Never felt the pressure	128 (85.33)
6.	Ill-treatment by clients/ their family	

	Yes	38 (25.33)
	No	112 (74.67)
7.	Instances of physical or mental harassment by clients/ their family	
	Yes	24 (16)
	No	126 (84)
8.	Instances of caste-based discrimination	
	Yes, severely	13 (8.67)
	Yes, to a smaller extent	25 (16.67)
	No	112 (74.67)
9.	Concerns due to separation from family	
	Difficulty staying away from children	41 (27.33)
	Illness of family members	6 (4)
	Issues with partner/ relatives	5 (3.33)
	N.A. since part-time job	15 (10)
	N.A. since no family	8 (5.33)
	No issues as such	75 (50)

5.16 Tackling Disputes with the Clients and their Families

Lack of compatibility and difference of opinions is not unheard of in an employer-employee relationship. Unpleasant interactions some HNs had with some of their clients and families have already been discussed. When any such situations of tension or trouble occur, more than 90% of the caregivers would consult their agency owners. It is instructed in their agency rule books that any conflict or matters of harassment from the clients' side be brought to the agency's notice. The remaining seemed to inform their families or co-workers when they had issues with

the employers. When the problem between the two parties is not severe, the nursing agency instructs the HN to adjust for a few days and see if issues are resolved. More than one-third of the sample was of the view that this is the first step their agencies take when they complain about the difficulties at their workplaces. In cases where the matter is severe and when the HNs inform the agencies that they can no longer stay with the clients, the agencies see to it that they let the HNs leave the contract. In such cases, the agencies replace them with other employees. If there are cases of harassment of female employees who take care of male patients, the agencies make sure that they assign male caregivers as the replacement. More than half of the caregivers found their agency members cooperative enough to understand their situations and help them come out of such troublesome contracts.

5.17 Clients' Remarks on the Caregivers' Nature: Personal and Professional

As stated in the previous chapter, the caregivers' lack of commitment to the job was the major shortcoming as perceived by the clients. Some also cited the HNs' interference in personal matters of the client's family, involvement in theft, and the morally weak characters of some female caregivers. Not all clients who took part in the study shared good bonds and had pleasant experiences with their caregivers. Mainly, the clients who had hired multiple caregivers had different stories to share. Some recalled instances of the HNs ill-treating the patients. They referred to such HNs as 'unprofessional' and 'inhumane'. Though mostly female caregivers were accused of being morally weak, one of the clients reported the instance of a male caregiver developing a love affair with their housemaid. The family had no other way than dismissing the caregiver and hiring another man acquainted with them.

The case of a client who had trouble with some of their care providers is presented below.

Case - 09

Raghunathan and his family have been using home nursing services for almost seven years. His mother-in-law is the patient. She has been suffering from osteoporosis and had broken her ribs and backbone earlier. She also takes medicines for diabetes. As the patient is confined to bed, assistance was required for activities like bathing, feeding, diaper and catheter care.

The respondent is a retired engineer, and his wife is employed. Being a nursing superintendent at a hospital, Raghunathan's wife has always made it a point to monitor how the home care providers took care of her mother. The couple has two married daughters who reside with their spouses and children. As none of them was available regularly, a formal caregiver was required to take care of the patient's health. They wanted a female caregiver, aged less than 50 years, physically strong, and someone who followed proper hygiene measures. They were not bothered about the caregiver's caste and appeared satisfied with people from backward castes as long as they maintained cleanliness. However, the family preferred a person from any other community to a Muslim person.

The family has a long experience of being with caregivers, and over seven years, about 55 different persons have worked for them. Raghunathan had to depend on several nursing agencies across the district to hire them. There have been people who worked for a handful of days. Most of them remained for a couple of months. The maximum a caregiver stayed with them was for two years. The family employed the caregivers solely for the patient's care, and they had a maid to look after the household chores. The respondent remembers that the caregiver's salary during the initial phase was 6,500 rupees, and now it has reached 15,000 rupees.

There have been cases of caregivers verbally and physically abusing the patient. Once a lady was caught beating the patient, she was sent back from the workplace after the issue was reported to the nursing agency with which she was associated. Though the patient was incapacitated, she used to be aggressive with the caregivers, who did not treat her well. She was on good terms with the ones who took good care of her, and she used to call them 'Molu' (which means daughter in Malayalam). Despite the good care they provided, the patient's health condition has not improved as such.

The family opines that the majority of the caregivers are serviceable, good people, and most of them have complex family backgrounds. Several of their caregivers hailed from broken families, many being divorcees or having abusive relationships. The family has experienced petty theft issues from some of these people. Items like bed sheets and mats were stolen. Also, some had to be kept at a distance as they unnecessarily involved in the family's private matters. He attributes this to the fact that they are formally employed in a private setting like home. So they might try to take it for granted and enjoy the freedom if the client's family is lenient. He informs that not all families would entertain such people. Another thing he does not like about some caregivers is their excessive use of mobile phones.

The patient is someone who likes the company of others. Since the family members could not provide it always, Raghunathan admits that the care providers have been a great support for her both mentally and physically. He adds, "home nursing services have become an inevitable part of our family life. Though several caregivers in the industry are not nursing qualified, many of them have learnt to perform many health care tasks due to their experience in the field. For this reason, Raghunathan finds the label 'Home Nurse' apt for these care providers.

Plate 5.2: The patient (Raghunathan's mother-in-law) and her caregiver



Source: Fieldwork

A client named *Seeniya* commented on the nature of caregivers their family had hired. She stated, *“I have seen caregivers who do not have any sincerity to the job. They do not have any commitment to the patient or genuine interest to improve their health condition. They express love and concern to the patients just for the sake of convincing the employers’ families. They are in the job merely to meet their economic needs. While some involve in theft, some others persuade the*

clients to give extra money. It will be unfair if I do not mention that some empathetic and caring people are in the field. One of the caregivers we hired had a good rapport with the patient, and he used to tolerate the patient's aggressive behaviour and temper tantrums".

5.18 Discussion

This chapter has depicted the value several caregivers and care receivers place on the quality of relationships they build with each other. Serving elderly and bedridden patients, and forming family-like connections with the clients and their families have often been the best part of their job for several caregivers. Similarly, most clients had a high opinion of caring, loving and trustworthy home nurses who are a real helping hand. Research has suggested that “the devaluing of home care workers and their labour may be compounded by their association with elderly and disabled people who are, themselves, held in low social regard” (Aronson and Neysmith, 1996, p.61). The current study's home care providers identified caring for the elderly and disabled by building meaningful bonds with them as one of the most valued elements of their work. This reveals that the aspect that is perceived to lower their work status is often that one thing many caregivers derive the most satisfaction from. However, the research participants seemed worried about the lack of recognition and appreciation despite their immense satisfaction with their jobs.

England (2005) accentuated the “idea that the recipients of care will be better off if the person giving care really cares about them than if they are motivated strictly by money” (p.389). In the current study, though most of the respondents from both categories seemed to support the idea of emotional attachment between the patient and the caregiver, there have been cases of formality and detachment. While some believed that strong bonds could positively influence the

patient's health, a few others seemed to oppose over-involvement of the HN in the patient's life and the patient's over-dependence on the caregiver.

Findings of research by Henderson (2001) suggest "emotional engagement as a requirement of excellence in nursing practice" (p.133). Eustis and Fischer (1991) discovered "clients confiding in their caregivers and discussing personal matters such as physical problems and needs, issues concerning their families, and sometimes their worries and fears" (p.451). Stone (2000) makes mention of home care aides that become fictive kins to their clients when emotional attachment develops due to closeness. The author and several others, such as Berdes and Eckert (2007), observe the "use of metaphors by nurse's aides that are associated with family, relationships, and attachment to describe their caring attitudes" (p.341). The present research found similar usage of kinship terms by both caregivers and care recipients. While most caregivers considered it a sign of intimacy and were content in such terms of address, a few clients (for instance, the one in Christopher's case) did not entertain such closeness or let their caregivers have that liberty. An instance of a client's family introducing the caregiver to their neighbours as their distant relative has been presented in this chapter. It is not sure if they did it to exhibit their attachment with the caregiver or wanted to conceal the caregiver's employment from their neighbours due to the concern of getting ridiculed for purchasing care services.

Misra (2003) ponders over caregivers "distancing themselves from the patients upon the advice of the employers" (p.390). She expresses her dissatisfaction with the norms and rules delineating care work and interpersonal relationships. According to her, "good care is undermined by organisations, professionalisation and commercialisation that hinder and discourage getting close, giving gifts, or touching" (Misra, 2003, pp.390–391). Martin-Matthews and Sims-Gould (2008) argue about the dilemma care workers face when they are demanded to be "close at

distance” (p.73). Mahmood and Martin-Matthews (2008) also discuss the “homecare agency policies that prescribe strong boundaries between paid work and home life” (p.29). The nursing agencies in Kerala also set such boundaries and frame rules concerning the interactions between clients and caregivers. Despite that, several caregivers formed strong bonds with their employers and accepted gifts. While they discovered such connections, the agencies, however, did not seem to object though they admit that a certain degree of detachment is the ideal.

Research by Eustis and Fischer (1991) warns how informality can negatively affect caregivers and care receivers. They state that workers are prone to exploitation when their time gets devalued or when they overwork for the clients. Similarly, the clients could experience a “loss of control as employer or manager of their own care” (Eustis and Fischer, 1991, p.455). They conclude that “there appears to be a paradox: Informality is necessary for good home care, yet informality is a problematic aspect of home care” (Eustis and Fischer, 1991, p.455). The present study also found employers worrying about losing their privacy due to the strange caregiver’s presence and thus supporting formal relationships in the informal setting of a home. Comments made by the client named *Raghunathan* testify this.

Though a good number of clients expressed gratitude and satisfaction with the services they received, some opinions about the unprofessional behaviour of the caregivers, their lack of commitment to the work, and rare instances of caregivers ill-treating the patients were reported. A study of domestic workers in Kerala by George (2013) reveals that employer satisfaction is often used as the yardstick to assess the workers’ professionalism. Nevertheless, the author conveys the

“difficulty in generalising satisfaction levels since employers have varied expectations and relate to the workers in different ways” (p.72).

The existing literature provides evidence for conflicts and tensions in the caregiving relationship despite the overall satisfaction of both parties in the process. Caregivers were seen complaining about verbal and physical abuse, work overload, unhygienic environments, and lack of decent living conditions, among others. Chichin (1993) finds several individuals unhappy about being regarded as maids and burdened by clients with excessive workload (p.175). Several others also discuss clients’ families’ “interference with the work of home care providers by unfairly complaining about worker performance” (Kaye, 1985, p.316). However, another study reveals that the majority “did not find anything difficult for they loved their work” (Chichin and Cantor, 1992, p.96). Similarly, in the present research, more than half of the caregivers did not dislike anything about their job. Ward-Griffin and McKeever (2000) report an “exploitative relationship between family and professional caregivers since the former was making greater contributions than nurses in terms of physical, emotional, and intellectual labour” (p.100). As opposed to this, clients in the present study did not remark that the home nurses contributed less than what was expected of them. It has already been discussed in the previous chapter that most of the patients’ kin stepped down from the primary caregivers’ roles after the HNs were hired.

Palriwala and Neetha (2010) note that live-in workers are more “vulnerable to physical, sexual, psychological or other forms of abuse, harassment and violence because their workplace is shielded from the public and they generally lack co-workers” (p.14). They also discuss that domestic workers ought to have “decent living conditions that respect their privacy” (p.14). Though several caregivers and agency owners in the current study advocated for decent work conditions, hardly anyone seemed to be concerned about the caregivers’ privacy. A few HNs have

spoken about respecting the privacy of the clients' families, but none of them expected the care receivers to provide them with the same kind of privacy since their work setting is the latter's home. The caregivers are often under the observation of the client's family when the relatives co-reside. Some clients' families have complained of the caregivers' over-use of mobile phones, while others were seen critiquing the caregivers enjoying their leisure time. This could be why some HNs mocked that several clients expect them to work like machines. Barer (1992) comments on the "home care worker's ambiguous worksite which lacks structure, supervision and the presence of coworkers" (p.136). The author also speaks about the absence of moral support and reports that "the home care worker goes to work in a strange setting while the recipient remains at home in familiar territory" (p.136). Xiao et al. (2020) view that "an unfavourable work environment contributes to the caregivers' poor health and well-being, perceived burnout and low level of job satisfaction" (p.2). A considerable number of care workers in the present study reported having experienced feelings of isolation, boredom and lack of freedom. Rejimon and Gopal's (2020) study of domestic workers in Kerala found that "membership in any domestic workers organisation is very essential to improve their status and condition" (p.62). In the present study, barring a couple of caregivers, nobody seemed to be concerned about employee unions' role in addressing their issues or ameliorating their work conditions.

Mahmood and Martin-Matthews (2008) share instances of "care workers not reporting cases of abuse to the agency for the fear of losing their jobs" (p.21). The current research also found parallels, and the case of Mariakutty, who remains silent about harassment, exemplifies this. There were also reports of clients' discrimination of workers against caste. While some employees from lower caste backgrounds were victims of ridicule or abuse by their upper-caste clients, HNs who hailed from upper castes never reported such bad experiences. Instead, they were found

explaining their helplessness and financial conditions that made them take up hands-on care despite their caste affiliations. They consider care work to better suit people belonging to lower castes. The challenges faced by some male caregivers have been explained through a couple of case studies. The very nature of the job that contradicts the gender roles prescribed to men was seen to restrict some respondents from revealing their work identity in public though they take pride in the excellent work they perform.

The present study also attempted to identify caregiving partnerships and the extent of informal caregivers' involvement in the process. The compensatory model of care was seen prevailing in the least number of cases from the perspectives of both caregivers and care receivers. As reported by the HNs, informal caregivers played the dominant role in one-third of the cases. The task specificity model was also observed in a considerable number of cases. This throws light on the fact that most of the clients' relatives associated with the study's sample did not withdraw from the caregiving process. However, the significant numbers of cases of substitution point towards a move to consider caregiving as the HNs' sole responsibility.

The next chapter deals with a summary and conclusion of the study findings and analyses.

Chapter 6

Summary and Conclusion

Universally, the provision of care to its members is deemed one of the crucial functions of the social institution called family. In a country like India, the caregiving roles and responsibilities have often been influenced by cultural values such as familism, filial piety, and family cohesion. However, change in cultural values is believed to have impacted caregiving decisions and brought about variations in caregiving practices, such as the willingness to receive support from sources external to the family. Over the past few decades, home-based caregiving arrangements in the country in general, and in the state of Kerala in particular, have witnessed an extension due to the inclusion of additional members as full or part-time caregivers.

This research set out to understand home-based care in Kerala by focusing on the different stakeholders in the care industry: caregivers, care receivers, and care facilitators. The major aims were to investigate individuals' reasons and motivations to don the role of in-home caregivers, identify families' rationale to outsource their function of caregiving, explore the nursing agencies' role in the process, and analyse the nature of associations formed between the care providers and care recipients in the process.

The findings reveal a gender imbalance in the domiciliary care sector due to the preponderance of women who consider the caregiver's role as an extension of their gender roles. Financial considerations, the job's relatively decent salary, personal or familial issues, and genuine interest to serve the ailing have influenced individuals to engage in the sector. Some people who

had faith in Christianity considered it a virtuous act to render care to the diseased. A considerable number of middle-aged widows and divorcees among the caregivers (home nurses) could be indicative of the liberty spouseless women have in choosing their occupation. Further findings demonstrate that caregivers who lead complex personal lives or lack familial support consider the job a liberation from their problems since it helps them get rid of boredom, emotional strain, loneliness, or abusive relationships. For such people, the role of live-in caregivers has offered psychological support besides financial independence. While a few male caregivers took up the role on the influence of their spouses who work in the same field, the salary and the ease of the job were the factors that attracted most others. It is worth noting that the job fetched several caregivers better earnings than their previous jobs. The nursing agency owners confirmed that none of their staff quit the job due to salary concerns. Furthermore, people of both genders have left better-paying jobs and continue in home-based care for the rewarding experiences it offers.

The industry has only a small cluster of graduates and academically nursing qualified caregivers. Several home care clients' remarks on home nurses as unqualified personnel reflect the societal perception that these caregivers are incapable and/or underequipped to attend to the medically oriented needs of patients. The caregivers' accounts also reveal that most nursing agencies do not impart intensive training to perform healthcare tasks. However, many of them carry out such functions based on their experiential knowledge, particularly the exposure they received while undertaking the role of bystanders for their hospitalised clients. This indicates their willingness to learn and perform nursing tasks done by clinic-based nurses. A few caregivers who previously worked as staff nurses, attendants, and janitors at hospitals can deal with the healthcare procedures, though their expertise levels and range of knowledge vary. Barring a small section that is scared to perform these tasks due to the apprehension of doing the procedures wrongly, all

caregivers are interested in accomplishing nursing tasks that are capable of raising the value of their role.

Though they realise their job's worth and consider it a laudable service, many seemed to be worried about the marginal status caregivers have in society. The negative connotation and stigma attached to the 'body work' they perform have led some to disguise their work identities. The fear of humiliation and the misperception of all female caregivers as morally weak was evident from several narratives. Most caregivers avoid working for known people and do not undertake contracts nearby their homes. The challenges facing male caregivers are explicit from some case studies in Chapters 2 and 4. The very nature of the job that contradicts the gender roles prescribed to men coupled with the performance of work in a setting outside public view (client's home) intensify the stigma by twofold. Ironically, the caregivers who claimed taking pride in the good work they perform were not gutsy enough to reveal their work identities to their friends and relatives. It must be mentioned that a handful of male employees opposed the sex-typing of the job, for they believed caregiving should not be earmarked as apposite to one gender.

Albeit the agency owners claimed that the illness condition and gender of the patient decide the caregiver's salary, the caregiver's gender seemed to have an impact. The study discovered a gender pay gap in the industry as several agencies did not pay their female employees at par with their male counterparts. The caregivers' salaries reveal that men earn approximately 2500 rupees more than women. The agency owners indicate that male caregivers are scarce in the profession, and higher wages have to be paid to retain them. While some claimed that looking after male patients was taxing, others reported the male employees demanding more payment. Most male caregivers' awareness of physiotherapy also seemed to set them apart from the females and became

a rationale for some agency owners to justify their higher pay. Though it was not made explicit, several agency owners uphold a pro-male bias, thereby affirming that the gender wage gap is real.

Chapter 2 discussed the different job titles used for domiciliary care workers across countries. This study did not identify any differentiation in job titles of the caregivers based on their expertise or nursing qualification. All the employees are referred to by the English term 'Home Nurse' and not any equivalent *Malayalam* term. Most caregivers are content with this job title as it raises the value of the work and boosts their confidence. Many acknowledged that the label had given them more dignity because they would have been equated to maids or servants otherwise. Nonetheless, the title was disfavoured by some academically qualified caregivers who consider it to downgrade their skills, a few male caregivers who regard it incompatible with their masculine identity, and some female caregivers concerned about the term's negative connotation. Most care recipients believe that those caregivers capable of performing the healthcare tasks, regardless of their academic nursing background, deserve the title 'Home Nurse'. Some clients suggested the title of 'care assistant' as an alternative since it would remove the ambiguity caused by the word 'nurse' in the existing job title.

The home nursing agencies' role as facilitators of care was explored by focusing on how they respond to their clients' caregiving needs, manage their workforce and clientele, and put forth strategies to regulate care giving/ receiving and sustain in an industry with ever-increasing competition. Their reasons for establishing a venture in the care industry reveal that nearly half of the agency owners were influenced by greater missions than profit motives. Creating jobs for the unemployed (particularly for unemployed women) and providing care for the ailing have been cited as the primary intentions. In that way, the agency owners who prioritise philanthropic

motives and focus on creating social value with their services can be considered social entrepreneurs.

Most of the agency owners believe that the services of home nurses have become inevitable, especially for the care of the elderly whose kin caregivers do not exist or co-reside with them or are formally employed. In their advertisements, many agencies emphasised that their staff would take complete care of the patient by treating them like a family member and sharing the responsibility of the patient's kin. These agencies publicise the idea that home nurses can become substitute caregivers for patients' relatives who are incapable, unavailable or indifferent to providing caregiving services by themselves. This portrayal of the home nurses and their work gives an impression that they can become the patients' fictive kin, indirectly hinting at the declining role of families in providing hands-on care to their members.

George's (2013) study of an organisation named Self Employed Women's Association (SEWA) in Kerala casts light on professionalising domestic workers by focusing on their training. The present study finds that, barring a few organisations, such as the Red Cross Society, the majority of the private nursing agencies do not seem to be bothered about the educational qualification or healthcare training of their staff. The caregiver's physical strength and enthusiasm to carry out their duties seemed more significant than their nursing skills or academic standards. Only a few agencies acknowledged that being equipped with healthcare tasks could improve the respectability and social standing of the home nurses. This study recognises the need to conduct intensive training programs to enable the caregivers to gain basic nursing knowledge and attend to their clients' healthcare needs adequately. As cited by agency owners, the reasons for the employees quitting their jobs include difficult work conditions at the workplaces, lack of freedom, isolation from family members and co-workers, getting better job opportunities, and ill health that

restricts performing arduous physical tasks. Mentions were made about staff who have continued for decades and some who have been working since the agencies' inception. Nevertheless, it is envisaged that better training on healthcare tasks and decent employee benefits would attract and retain good workers in the industry and pave the way for enhancing the respectability and worth of the profession.

The nursing agencies try to regulate the relationships and interactions between the clients and employees by setting up several guidelines that both parties involved in a contract must adhere to. The agencies chart a care plan for each customer, and the home nurses are supposed to work accordingly. To ensure compliance with the norms, the care providers are clearly instructed not to deviate from the plan. The staff is asked to bring it to the agency's notice if they face any difficulty at a client's place or the client/ family tries to take advantage of their services. They make all efforts to ensure the safety of both parties, with a particular concern for the security of female caregivers. Before an employee undertakes a contract, the agency instructs them on the etiquette to be practised with the client and family. Several agencies advised their staff not to over-involve in the clients' family matters, whereas some warned them to ensure the elderly patients do not become over-dependent. Despite this guidance, some caregivers formed strong ties with their employers and accepted gifts. While they discovered such connections, the agencies, however, did not seem to object though they admit that a certain degree of detachment is the ideal.

Home care clients in the present study were majorly elderly patients with age-related or terminal illnesses, patients of other age groups that either suffered from chronic lifestyle diseases or required post-surgery care and assistance, and young women who needed postnatal care. The care needs of the clients varied. While some required medical treatment and nursing (healthcare), assistance with daily activities (personal care) would suffice for the other. A few clients did not

have any serious health concerns but required the caregiver's company as their family members were absent throughout/ most of the day. Quite a few families sought the home nurse's help with some household chores for additional pay. Some elderly patients also wanted their caregivers to read and discuss daily newspapers, share stories or chitchat to evade loneliness, and read religious scriptures or recite prayers. Such caregivers provide "holistic care that addresses the care recipient's physical, mental, and spiritual needs" (Hermanns & Mastel-Smith, 2015, p.8).

Research has found that numerous care workers recognise "psychological support offered to frail and isolated patients as the main task they performed" (Chichin and Cantor, 1992, p.96). Similarly, home nurses in the present study value emotional support and assistance they render to their clients even more than or as much as the performance of nursing procedures. According to them, the most-needed qualities of a caregiver ordered in a hierarchy are patience, passion for looking after the sick, commitment to the job, cleanliness and hygiene, and the ability to fulfil the patients' healthcare needs. As per the clients, a caregiver's indispensable qualities are their caring nature, trustworthiness, patience, honesty and cleanliness. Akin to the caregivers' opinion, the ability to perform healthcare tasks did not seem significant to them. While discussing the low status of care workers, Aronson et al. (2004) opined that the disregard for the job could be "associated with the needs of elderly and disabled people who are themselves held in low social regard" (p.112). Though the above-said categories of patients might have low social standing, caring for them has been cited as one of the best-liked aspects of the job by a substantial number of home nurses in the current study.

The clients' families had specific criteria to hire a caregiver. While characteristics such as gender, age, and physical fitness were prime to all the clients, aspects such as educational qualification, marital status, and physical appearance took a back seat. Though physical

appearance or beauty is not a criterion, many hinted that they wanted the caregiver to appear neatly groomed and clean. Clients who required assistance with household chores expressed the desire to hire someone who cooks and eats foods of their liking. Despite dismissing the caregiver's caste as a selection criterion, almost half of the clients were found to have hired people from their own castes. A disinterest in hiring persons belonging to lower castes, tribes, and Muslim communities was noted in some cases. Many caregivers and agency owners confirmed the clients' preference for people of their own or certain other communities. Instances of the caregivers misinforming their castes to match with the clients' preferences were also reported. Overall, the clients seemed to ensure that the caregivers had cultural compatibility and some degree of commonality with them.

A preference for female caregivers to take care of male patients was observed, the primary reason being the unguaranteed safety of the family members due to employing a strange male caregiver. But, some clients' kin view that male patients require caregivers of the same gender, especially to impart intimate care. In some such families, the patients' female relatives barely interacted with the male caregivers for fear of being accused of illicit relations. The case of an elderly patient who stayed with the caregiver in an outhouse elaborated in Chapter 4 demonstrates the family's strategy to accommodate the male caregivers while maintaining distance from them. Nonetheless, shifting the patient from the house to make an alternate arrangement also reflects the willingness to make modifications within the family to enable the caregiving setup. Several other clients' families ensured the patients' access to equipment such as specialised hospital beds, devices such as dialysis machines, wheelchairs, walkers, among others, to make the best possible care available at home.

Many clients were found to prefer middle-aged caregivers to caregivers aged below 40 years. The former is considered appropriate as they are generally believed to manage all household affairs efficiently and adequately carry out caregiving tasks. That said, hiring a person above 60 years is deemed risky since they are more likely to suffer from illnesses. Despite their advantage of being physically strong, some complexities are associated with hiring young caregivers. These include the impatience of youngsters to attend to the needs of elderly clients, their perceived inability to bond well with the elderly care receivers due to the generation gap, their involvement in theft cases, dissatisfaction with the work environment and facilities, excessive usage of mobile phones, and suspicions about young women developing illicit relationships with the clients' male relatives. Middle-aged caregivers are perceived better capable of offering emotional support to elderly clients who yearn for companionship.

The home care clients' reasons to outsource care were examined. Previous research has found that "Kerala has a very low incidence of joint families, and the general trend is towards adoption of nucleated residence" (Eapen and Kodoth, 2002, p.18). Concurring with this, most clients in the present study seemed to consider the shift to nuclear families as the cause to opt for formal care. However, their decisions to hire the caregiver were influenced by other factors. A marked shift in families' attitudes can be witnessed in the beliefs that care can be given/ received regardless of kinship ties, and their caregiving duties can be delegated to others. The apprehension that their care may not suffice to meet the patient's growing needs also seems to impact the decision to purchase care. There have been arguments on "working women's income increasing their ability to finance home care" (Stoller, 1989, p.48). A handful of formally employed primary caregivers who supported this notion considered it sensible to engage home nurses. They voice that their employment fetches enough money to employ care workers who can provide the requisite

services as their proxy. The significance of dual-earner families, the aspiration to have improved living standards, and the principle of rationally prioritising one's tasks and needs were explicit from their narratives. This proves that domiciliary care has also become normal due to the preference to seek professional help, employment of the primary caregivers and their unavailability to render care.

Recent research by Ugargol & Bailey (2018) underscores “Kerala’s demographic transition and emigration of primarily male adult children” who leave behind their elderly parents and other family members. In several such cases, “daughters-in-law sacrifice their careers to take up caregiving roles” (Ugargol & Bailey, 2018, p.194). The present study also came across NRI families with employed daughters-in-law as the primary caregivers. The efforts of home nurses who became surrogate caregivers to save these women from sacrificing their careers are worth mentioning here. Some kin caregivers (especially daughters-in-law) were troubled by the elderly patients’ uncooperative behaviour during bathing and toileting them, or were hesitant to provide personal care, especially to patients of the opposite gender. The issue was sorted once they could shift this responsibility to the home nurses. On the whole, it appears that the paid caregivers not only helped the unpaid caregivers balance their personal and professional lives but also relieved them of the caregiving duties that they found uncomfortable or tiresome.

“As increasing proportions of women enter the paid labour force, a care deficit emerges that requires drawing in the labour of other women, who leave behind a care deficit in their own household” (Raghuram, 2012, p.155). When home nurses become the substitutes who fill the care deficits created by the clients’ informal caregivers, they create care shortfalls in their own families. This is exemplified in the cases of *Saleena*, whose sons stay in a hostel run by a religious institution, *Binoy*, whose daughters are taken care of by their grandparents, and several others who

resort to part-time work to take care of ailing family members or adolescent children. The inability to properly care for one's family due to detachment from them was cited by some caregivers as one of the challenges posed by their job.

A study by Rajan and Arya (2012) demonstrates that the majority of the aged in the state choose to stay with their families. The present study also confirms this, and the clients' kin disfavours institutionalisation of the elderly patients into care homes. Some of them made it explicit that sending one's ailing relatives to residential care homes invites scorn and humiliation from society. In such cases, in-home care seemed to be a safer alternative. However, it must be noted that the families' decisions to employ the caregivers were not easily made. Most clients realised the need to have formal help when the care requirement exceeded their capabilities. These situations include falls or accidents resulting in surgeries, and sudden deterioration in health, which made it hard for the primary caregiver to manage the care solitarily. Clients hiring postnatal caregivers without genuine requirement but on the influence of their social networks were also occasionally seen.

The nature of caregiving associations between paid and unpaid caregivers has been explained in the introductory chapter through different frameworks viz. Cantor's (1991) hierarchical compensatory model, Edelman and Hughes's (1990) supplementary model, Greene's (1983) substitution model, and Litwak's (1985) task specificity model. This study analysed the relationships from the caregivers' and care receivers' perspectives to identify the kin caregivers' involvement in the process. The compensatory model of care was seen prevailing in the least number of cases from both perspectives, indicating that families continue to provide care to their members, though the extent and nature vary. In about one-third of the cases, the home nurses played supplementary roles when the patients' families were the dominant carers. The task

specificity model was also observed in many cases, thereby reflecting the segregation of duties between the two types of caregivers. The numbers corresponding to these three models mirror that the clients' relatives do not withdraw from the caregiving process. However, the significant numbers of cases of substitution from both perspectives (refer to figures 5.1 and 5.2) point towards a move to consider caregiving as the home nurses' sole responsibility.

In several cases, the relationships between the caregivers and the clients' families seemed to affect the former's role performances. As they developed friendly or family-like relationships with the clients' families, some female caregivers volunteered to help with chores even if the duty was not formally a part of their care plan. They tend to empathise with the patients' female kin who otherwise have to perform the household chores singlehandedly. This acceptance of role ambiguity is based on mutual informal agreements and is felt to be advantageous to both parties. Many caregivers were offered financial support and expensive gifts by their clients as a token of love and appreciation for their sincere services. Clients helping previous caregivers with a satisfactory record by referring them to their relatives or acquaintances was also common. The narratives of some home nurses reveal that reciprocal partnerships with clients' families are an enriching aspect of their job as it helps boost their social capital.

Findings of research by Henderson (2001) suggest "emotional engagement as a requirement of excellence in nursing practice" (p.133). Eustis and Fischer (1991) discovered "clients confiding in their caregivers and discussing personal matters such as physical problems and needs, issues concerning their families, and sometimes their worries and fears" (p.451). Stone (2000) makes mention of home care aides that become fictive kins to their clients when emotional attachment develops due to closeness. The author and several others, such as Berdes and Eckert (2007), observe the "use of metaphors by nurse's aides that are associated with family,

relationships, and attachment to describe their caring attitudes” (p.341). The present research found similar usage of kinship terms by both caregivers and care recipients. While most caregivers considered it a sign of intimacy and were content in such terms of address, a few clients did not entertain such closeness or let their caregivers have that liberty. The instance of a client’s family introducing the caregiver to their neighbours as their distant relative has been presented in Chapter 5. It is not sure if they did it to exhibit their attachment with the caregiver or wanted to conceal the caregiver’s employment from their neighbours due to the apprehension of getting ridiculed for purchasing care services.

It has been recognised that despite being “necessary for good home care, informality is a problematic aspect” (Eustis and Fischer, 1991, p.455). The present study also found employers worrying about losing their privacy in the strange caregiver’s presence, due to which they support formal relationships in the informal setting of a home. Though many caregivers and agency owners in the current study advocated for decent work conditions, hardly anyone seemed to be concerned about the caregivers’ privacy. A few home nurses encouraged respecting the privacy of the clients’ families, but none expected the care receivers to provide them with the same kind of privacy. The caregivers are often under the observation of the client’s family when the relatives co-reside. Some clients’ families have complained of the caregivers’ over-use of mobile phones, while others were seen critiquing them for enjoying their leisure time. This could be why a few home nurses mocked that some clients expect the caregivers to work like machines.

Though a good number of clients were appreciative of the services, some opinions about the unprofessional behaviour of the caregivers, their lack of commitment to the work, and rare instances of caregivers ill-treating the patients were reported. Ward-Griffin and McKeever’s (2000) study reports an “exploitative relationship between family and professional caregivers since

the former was making greater contributions” (p.100). As opposed to this, clients in the present study did not remark that the home nurses contributed less than expected. It is evident from the discussions in Chapter 4 that most of the patients’ kin stepped down from the primary caregivers’ roles after the HNs were hired. Analysis of the caregivers’ most disliked aspects of the job reveals that the majority did not find any faults with their work. The remaining were found citing issues such as bitter relations with clients, demanding work conditions and work overload, the negative societal perceptions about home-based caregivers, inconsiderate behaviour of some patients, and ill-treatment from the clients and/or their families.

Mahmood and Martin-Matthews (2008) share instances of “care workers not reporting cases of abuse to the agency for fear of losing their jobs” (p.21). The present research also found parallels, and the case of *Mariakutty*, who remains silent about harassment, epitomises this. There were also reports of caste-based discrimination. Some employees from lower castes were victims of ridicule or abuse by their upper-caste clients. They were asked to sleep on the floor, instructed to sit in the kitchen/ on the floor to have food, not allowed to use the common washrooms or toilets inside the house, and denied some special food items. However, caregivers who hailed from upper castes never reported such bad experiences. Instead, they were found explaining their helplessness and financial hardships that led them to take up hands-on care despite their caste affiliations. They consider care work to better suit people belonging to lower castes.

Xiao et al. (2020) view that “an unfavourable work environment contributes to the caregivers’ poor health and well-being, perceived burnout and low level of job satisfaction” (p.2). A section of care workers in the present study reported having experienced feelings of isolation, boredom and lack of freedom in unfriendly work settings. Rejimon and Gopal’s (2020) study of domestic workers in Kerala found that “membership in any domestic workers organisation is

essential to improve their status and condition” (p.62). In the present study, barring a couple of caregivers, nobody seemed to be concerned about employee unions’ role in addressing their issues or ameliorating their work conditions. It is envisaged that unionisation could be instrumental in ensuring safer and decent work settings for domestic care workers.

When it comes to their satisfaction with the job, the majority seemed to be satisfied or very satisfied in their roles. The significant sources of satisfaction were the joy of serving the ailing elderly, the clients’ contentment with their services, and meaningful ties formed with the patients and their families. Correspondingly, most home nurses consider their work easy or moderately easy. None declared their job as very difficult. However, time and again, many stated that their work was not a bed of roses. The major factors that made the caregiver’s role difficult are the nature of the patient’s illness, and relationships with the clients and their families. The care of stubborn and mentally ill patients who become agitated is often considered risky. As far as the care recipients’ satisfaction with the services is concerned, the caregivers’ relationships with them seemed to be a contributing factor. Most of them reported moderate to good satisfaction levels resulting from the caregivers’ affection and concern for the patients. Many were appreciative of the caregivers’ character and were pleased to find the patient comfortable and happy in the caregiver’s company.

England’s (2005) work on ‘theories of care work’ discusses different perspectives associated with the job. The ‘devaluation’ perspective underlines that cultural biases hinder wages and state support for care work due to its association with women (pp.381–382). However, the present research participants do not link this gender association to the lowered status of their job. Another framework titled the “prisoner of love” highlights “altruistic motivations for and intrinsic rewards of care work and that these may lead care workers to accept low pay” (England, 2005,

p.382). This framework is supported by Lightman and Kevins (2019), who argue about care workers' "better job satisfaction than equivalent workers outside of care work, due to the impact of nonpecuniary benefits such as helping others or building relationships with clients" (p.12). The present study backs this framework as a substantial number of caregivers seemed content with the intrinsic rewards. The perspective can be witnessed in the case studies of *Binoy*, *Kumari*, and a few others who left better-paying jobs and continue in domiciliary care for the rewarding experiences it offers. The job's effect on improving the workers' social capital has already been pointed out. This research disagrees with the "commodification of emotion" framework, according to which "care work generates additional stress and/or alienation for the worker, thereby resulting in lower job satisfaction" (Lightman and Kevins, 2019, p.1). Though care gets commodified, it is not often at the cost of alienating the caregivers from their work. The formation of meaningful bonds over time makes the process an instance of commodification without estrangement. This is illustrated in the stories of *Indu*, *Sajna*, *Kumari* and several others who find it hard to be separated from their clients even during their two days of absence from work.

To better comprehend the nuances in caregiving relationships, future research should have more patients who are the direct care receivers as respondents. This research could not include a greater number of patients due to their illness conditions and inability to communicate. The patients' kin who were their spokespersons would have had experiences and perspectives different from that of the patients'. Further research should include more joint families, explore their reasons for outsourcing care, and compare them with those found in nuclear families.

Cultural and familial norms, since time immemorial, have been governing by whom should and how should care be provided. As the family's caregiving function gets reassigned to external sources, the care recipients try to ensure that the caregivers have cultural compatibility and some

commonality with them. On the other hand, due to various obvious reasons, most caregivers prefer working with strangers and people who are not related to them. When extra-familial care becomes commonplace, a change in familial values become apparent. The economic rationality that motivates individuals to continue employment and get their caregiving jobs done by another illustrates this attitudinal shift. Despite informal caregivers playing significant roles in most caregiving arrangements, the extent of their involvement differs due to reasons such as women's participation in paid employment, the preference to seek professional help, and the patients' relatives' incapability or unavailability to provide care. A considerable number of home nurses shouldering the majority of the caregiving responsibilities casts light on caregiving becoming an activity that could be carried out regardless of the relationship between the caregiver and care receiver. Some caregivers' narratives on the elderly patients' kin not partaking in the caregiving process as much as anticipated point towards a failure of filial obligations. Paid caregivers often become a viable alternative, particularly for the care of the elderly and chronically ill. Given this trend of weakening informal support networks, several researchers speculate that formal caregivers will replace informal family care providers in the future. This research on domiciliary care calls for a re-examination of the functions of family. Just like how the caregiving function is fulfilled by strangers, other agencies could substitute the institution's functions, such as the socialisation of children. The present study, despite believing that the proliferation of the home care industry can weaken familial bonds, acknowledges that "formal caregivers help keep the elderly and/or chronically ill patients in the community, and thus sustain the informal caregiving arrangements" (Tennstedt, Crawford, & McKinlay, 1993, p.621). It also recognises home-based care as "a more client-centred and client empowering approach to nursing" (Brown, McWilliam & Ward-Griffin, 2006, p.160). Besides offering direct care to the patients, the home-based caregivers provide

assistive care to the patients' kin (particularly female relatives) by sharing their tasks and responsibilities. The study findings reflect that several home nurses play a significant role not only in the therapy management of the patients but also in their lives. When the significant others step down from their caregiving roles or lessen performing their familial obligations, caregiving agreements pull together two strangers, and the process often witnesses the strange caring 'other' becoming familiar.

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Appendix 1: Schedule for the Home Nurses

Informant ID:

PERSONAL DETAILS

Name/ Pseudonym:

Age:

Gender:

Caste/ Community affiliation:

Experience in the field (in years):

Educational qualification:

Any nursing background: Yes/ No

Registered with any nursing agency: Yes/ No

Family details (No. of members and their occupations):

Work-Related Details

1) What are your reasons to take up this job?

(a) Financial (b) ease of the job (c) interest to help and take care of ailing (d) religious/ service ethic (e) other

2) Do you think women are suitable to perform such jobs as nursing? If yes, was it also a reason that prompted you to choose the job? (Question for women)

3) Did you ever find the job easy because you felt that nursing/ caring is an extension of the role of a mother/ woman? (Question for women)

4) What aspects of your job make it difficult? On a scale of 1 to 5, rate the difficulty level

Very Easy	Easy	Moderate Ease/ Difficulty	Difficult	Very Difficult
1	2	3	4	5

5) If you were previously engaged in any other jobs, what were they?

6) What were the reasons for leaving the previous job?

(a) Dissatisfied with the pay (b) difficulty of the job (c) unfavourable working conditions

(d) Other

7) Are you only equipped with providing personal care tasks for the patient, such as bathing, feeding, toileting the patient, etc.?

8) What healthcare-related tasks can you perform (such as monitoring blood pressure, catheter care, giving medications or administering insulin?

9) How far has the job helped you in taking care of your own kin/ family members when they fell ill?

10) How does it feel to take care of a stranger? Taking care of a stranger v/s taking care of a known person/ relative? Which one do you prefer?

11) Would remuneration become an issue if you work for a known person?

12) What is it that prompts you to remain in the job? What is the fact that you like the most about your job? (ease of the job, interest to take care of the ailing people/ service ethic, the job fetches a decent salary that is enough to keep life going, making new bonds with people and expanding one's social network, etc.)

13) How much is your salary? Do you think male home nurses get paid more? Why is this so?

(Question for women)

Details of Clients and Families

14) Profile of the current employer:

- a) Caste/ community
- b) Financial status
- c) Family type- nuclear/ joint
- d) Occupational status of the members (especially female members)

15) What is the patient's illness?

16) How long have you been with the client?

17) Is it a full-time or part-time contract?

18) What reasons (you think) made them employ you?

19) Based on your past experiences, give these details about the clients during the last few years
(a maximum of 5 clients)

	Client A	Client B	Client C	Client D	Client E
Community/ Caste					
Family Type					
District/ Region and distance from your place					
Financial status					
Illness of the patient					
The age group of the patient					
Payment / Salary					
Referrals adopted by the clients (if any)					

Duration of the service/ contract					
Occupation of the family members (female especially)					
Tasks made to do					
Task segregation/ tasks not allowed to do					
Commensality (Yes/ No)					
Relationship with the client (matters they					

discuss with you)					
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Details on Relationship with Clients and Families

20) Where in the employer's home do you stay? In the same room as the patient?

21) How close are the patient's family members with you?

22) What topics do they discuss with you? Only those related to the patient's illness? Or family matters (both yours and theirs) too?

23) Do you all sit together and have food? Or, do you have a separate food time, place to have food, different utensils, etc.?

24) Are you allowed in the kitchen? Are there any spaces/ places in the home to which entry is denied for you? (other than private spaces)

25) Do the clients involve you in their family events or functions?

26) Do you remain in contact with the clients even after the contract ceases? If yes, the reasons for this contact (financial, maintaining the relationship, finding potential employers, etc.)

27) How are the client's terms and conditions? How flexible are the conditions?

28) How often do they allow you to go visit your family? Do you have access to contact your family members? Do you have any access to any recreational activities?

29) Do they give you instructions on how to care for the patient, or you can do things as you wish?

(Is it related to the patient's age, illness, etc.?)

30) Is there a prescribed routine that you have to follow daily? Does it depend on the patient's age and severity of illness?

31) How do the clients treat you? How do you want them to treat you?

32) How do you treat the patient? As a stranger? Or, like a kin/ relative? (Find the terminology used to address the patient)

33) Did your relationship and intimacy with the patient change over a period of time?

34) What all matters does the patient discuss with you? What are the topics discussed in the presence and absence of family members?

35) From various experiences you have had throughout your career, what are your expectations from a client? For you, what is a perfect nurse-client relationship?

36) Do you think the relationships with the clients vary with their financial/socioeconomic statuses?

37) Do you think the nature of the relationship with clients varies with their community/ caste affiliation and region? (For instance, are clients from a region/district X friendlier or clients from a particular caste/ community more cordial)

38) How do you think is the patient treated by their family members (for instance, if the patient is an elderly person? With love, respect, and concern? Do they spend enough time daily with the patient?

39) Have you ever felt that the family's concern for the patient is reflected in their behaviour towards you since you are the one who looks after the patient?

Problems Faced by Home Nurses

40) Do you have any health issues, such as physical discomfort? Does it depend on the patient's illness? Caring for which patients are more physically exhausting?

41) Did you ever face any psychological/ emotional issues such as feeling sad/ depressed and lonely, stressful life and routine, lack of freedom?

42) Any other issues due to staying away from one's own family? (Problems during early career Vs late career. Reasons, if any? (family burden, small kids, illness of family members, marital status, etc.)

43) Any problems such as role conflict or overload?

44) Do you find it difficult because you have to perform multiple tasks- household chores in addition to patient care? Does this contribute to role stress?

45) Were you anytime being treated like a servant? Are you given enough respect by the clients? Is the relationship between the client and the nurse one of mutual trust and respect?

46) Have you ever been accused of theft or any other issue that occurred at the client's home?

47) Do the clients make you work more than what you expect yourselves to be doing? Do you perform the tasks assigned to you (by the clients/agency) out of interest/compulsion or perceive it as a part of your duty?

48) What are the issues female home nurses who take care of male patients face? What is their family's (husband's or parents') reaction to taking up the contract?

49) Do the clients ask about your community/ caste affiliation? Did you ever feel that you were discriminated against caste anytime? (Any bad experience with any client anytime in your career?)

50) Have you ever faced an issue of physical or mental violence/harassment from the client or agency member?

Specific Questions to Educationally/ Academically Qualified

51) What are your reasons for being on the job?

(a) could not get jobs in hospitals? (b) not interested in hospital-based caregiving (due to more clerical work and less bedside care? (c) unhappy with hospital work conditions, rules, salary, regulations, and organisation? (d) others

52) How do you think hospital and home-based care are different regarding the Nurse-Patient relationship?

53) How do you find the power relations (between the client and the nurse) compared to hospital-based ones? Do you have enough autonomy in a home-based setting?

54) The ease of the job compared to hospital-based care?

55) How satisfied are you with the job? With the salary?

56) Are you registered with any agency? Or, do clients directly seek your assistance/ help?

Specific Questions To Male Caregivers

57) What are your opinions on nursing as a profession/ career. (Do you perceive nursing as women's forte?)

58) What are your educational qualifications and your prior work experiences (and compare this to that of the female HNs)

59) What are your areas of specialisation (for instance, male HNs may be into physiotherapy and such areas).

60) What are the reasons behind taking up this job? (Find the similarities with those of females)

61) Do you experience (have you ever experienced) any kind of stigma due to being in this sector? (that too home-based care) Is your work stigmatised or less respectable to be pursued as a career?

62) Are male HNs employed only to take care of male patients? Had a male HN anytime been employed for a female patient?

63) Do you prefer a particular category of patients? Do you like caring for patients suffering from specific illnesses?

64) Could you share any details on your remuneration/ payment? (compare this with that of female HNs)

65) If males are getting paid more than females, what could be the probable reasons?

(* men should be paid more than women *male HNs are better educated than their female counterparts? * male HNs are more competent than females? * male HNs are focusing on such specialisations that demand a higher payment? * male HNs are less in number and more in demand

for thus the ones getting employed get paid more? * male HNs perform additional/ supplementary tasks (such as driving) that require skills * since male nurses may get paid better than female nurses in hospital-based nursing, the same is replicated in home-based care?)

66) If you get paid more than your female equivalents, why do you think it happens?

67) What is your work schedule? Full-time or part-time work? Do you stay 24 x 7 with the client's family like the female HNs do?

68) If you don't, then what are the reasons? (home is nearby, can't stay away from family, have access to travel/ mobility, others)

69) How are your relationships with clients and their families? (find how it is different in the case of a female HN)

70) What are the tasks that are assigned to you, in addition to patient care? (driving, shopping duty, etc.)

Specific Questions to Caregivers Who Have Been Hospital Bystanders

71) Why do you think you had to be the bystander instead of the patient's family member or relative?

72) If there was also some patient relative who accompanied you, what tasks were you made to do? What did they do?

73) What were the illnesses the patients suffered from in those cases when you were made to stay alone with the patient? Does the severity of the disease decide the presence of family members?

74) Do you think taking care of the patient in a hospital scenario was also a part of your duty or contract/ agreement?

75) Were you comfortable with staying in the hospital setting?

76) What difficulties did you face in the hospital? (like not being able to sleep properly, being made to do too many tasks, etc.)

77) How was the experience in the hospital interacting with nurses, doctors, and other staff? Could you learn something that helped you care for the patient at home? (such as monitoring blood pressure, catheter care, giving medications or administering insulin, etc.)

78) Were you given any instructions by the nurses and doctors about the patient's care when they get discharged from the hospital? (anything on the diet, medication, etc.)

79) What duties/ tasks did you do when you were in the hospital, and those were done by the patient's family members when taken back home? (and vice versa)

80) If there is an issue/ problem with the client (such as a fight) or if you can no more manage the situation, who is consulted first? The agency? What is the policy, then?

81) How do you tackle the situation? Do they ask you to adjust for some more time, or do they replace your position with another HN?

Specific Questions to Part-Time Home Nurses

82) What is your work schedule- what all tasks are you made to perform?

83) Is there a demand for part-time home nurses? If yes, for patients suffering from what kinds of illnesses mainly?

84) Any information on your salary/ payment?

85) What are your reasons for taking this up as one of the pursuits? Personal issues? Or financial reasons?

86) What other work do you do in addition to this (if any). Or, if you do not find a job in this industry, what other choices are available to you?

87) Do you experience any kind of role strain or role overload due to engaging in multiple vocations? How do you manage both family life and work-life?

Specific Questions to Postnatal Caregivers

88) Were you (or your ancestors) a midwife or birth attendant earlier?

89) Are you registered with any agency?

90) How long are you usually employed?

91) What is your work schedule- what all is that you have to do? Care of the baby or care of both mother and baby? Do they do other household chores as well?

92) Do you think there is still a demand for your vocation?

93) Did you ever experience any kind of stigma?

94) What are your reasons for sticking to the job? (Payment?)

95) How much do you get paid?

96) Do your relatives hire you if there is a need for pregnancy-related care? (In such a case, would you be interested/ uninterested in going since it is a relative? Any concessions in the payment?)

97) Are there also some qualified nurses involved in postnatal care? If yes, is there a demand for them compared to the traditional midwives? Or, are the traditional ones preferred?

Questions About the Work and the Agency

98) Do you find any aspect of your work polluting or impure? (such as bathing and toileting the patient etc.) If yes, how do you deal with it?

99) Did you receive any kind of training from the agency? What kind of training did you receive from the agency?

100) What kind of suggestions, instructions, and commands were given by them regarding the job you have undertaken? Were you also told how to behave with the clients?

101) Were you told not to get emotionally attached to the patient/ their family? Were you instructed to be cautious so that you are not accused of an issue like a theft case?

102) Is there any kind of bond/agreement that is made with the agency with whom you are registered? Is there a minimum period that one has to remain with an agency?

103) How happy and satisfied are you with the agency's terms and conditions? Any issues with the payment?

104) How many agencies have you so far been associated with? What is it that you dislike about working with an agency?

105) Did you ever work anywhere without the agency being aware of it; if yes, why?

106) Did you ever work in another Indian state?

107) Do you get employed throughout the year? Or, do you find a job as soon as one contract ceases? If not, do you try finding another job?

108) In the case of home nurses who migrate (internationally), look at their work experiences, the differences and similarities between working abroad and working back home (factors other than salary), any problems or difficulties experienced in their career, the role of agencies in the migration process, etc.

109) How do you find the label '**Home Nurse**'? Do you like being called an HN?

110) How has the label had a positive impact on your life?

- ❖ It raises the value of my job
- ❖ I feel that my job is as good as that of a hospital nurse
- ❖ The label has given me more dignity
- ❖ It has replaced being referred to as a servant/ helper
- ❖ NA since I do not like the term
- ❖ No impact as such, just neutral
- ❖ NA since the label doesn't suit men
- ❖ No impact due to negative perception about the job
- ❖ A term like 'caregiver' suits better

❖ Better call me by name, do not prefer the term since I am not nursing educated

111) Overall satisfaction with the job (Very satisfied, satisfied, moderate satisfaction, dissatisfied, extremely dissatisfied)

112) If you are dissatisfied, what are the main reasons?

113) If you are satisfied, what are the reasons?

Appendix 2: Schedule for the Home Nursing Agencies

Informant ID:

AGENCY DETAILS

Name of the agency and year of establishment:

Owner's name/ pseudonym:

Experience in the field (in years):

Educational qualification:

Any nursing background: Yes/ No

Family details (No. of members and their occupations):

Registration details:

Any other branches of the institution:

Any other business run by the owner:

Questions About the Services Provided

1. How many home nurses are registered with the agency?
2. Do you provide both full time and part-time home nurses?
3. What kind of services do you provide other than home nursing?
4. Who are your clients? What is the caste/ religious affiliations of most of them?

5. Do you supply employees to other districts/ states?
6. Does the majority of the clients want the home nurses to perform household tasks and patients' care?
7. What are your reasons and motivations behind starting this venture?
8. What are the most common illnesses of your clients?
9. How do you select the employees?
 - ❖ Do you prefer people with some academic nursing background?
 - ❖ Do you select anyone from personal contacts or friends' circles?
 - ❖ Or, anyone who needs employment is selected?
10. Are there any screening tests for the candidates? Or, any random person would be employed despite their qualification, skill, experience, expertise, or interest in caring?
11. What procedures do you undertake when a new home nurse is employed? (Do you get police verification done)
12. What is the minimum requirement or criteria concerning educational qualification? (like, class X passed etc.)
13. Explain the training given to the nurses in detail. What kind of training? Are the home nurses given any sort of acquaintance with health care tasks (such as monitoring blood pressure, catheter care, providing medications or administering insulin etc.)?
14. Who gives the training? (Qualifications of the trainers)
15. Is there illness/ disease-specific allocation of nurses to the clients?
16. Are the home nurses specialised in the care of particular illnesses?
17. Are any referrals made by the existing home nurses to recruit further nurses? (such as their kin or acquaintances)

18. Are there migrant home nurses? If yes, how are they outsourced?
19. How long does a nurse registered with an agency remain in the job?
20. Overall, how satisfied are you with the home nurses working for your agency?
21. Any data on the remuneration of the home nurses?
22. Does the remuneration vary depending on the expertise and qualification of the home nurse, gender of the home nurse, type of illness the patient is suffering from, spending capacity/ spending power of the client, etc.)?
23. Does migration of the home nurses happen? In such cases, what is the role of the nursing agencies in the process?
24. Since both female and male nurses are there, are there any gender-specific selection criteria? (for instance, male home nurses need to be physically fit, healthy, non-alcoholic etc. OR female home nurses should not be unmarried etc.)
25. Is there a demand for male nurses?
26. Do clients hire female home nurses for the care of male patients?
27. Are male home nurses sufficiently available?
28. If there is a shortage, why do you think this happens? How do you tackle this? (by negotiating and allotting female home nurses to the clients instead of males? Sending the client to some other agency? Searching and finding a male nurse)
29. For patients suffering from which kind of illnesses are male caregivers sought the most?
30. Do you think those males who enter the industry are better qualified than their female counterparts?
31. Are male home nurses paid more?

32. Do they demand more payment (compared to women)? Or, do you think they are to be paid more since it happens in the case of many other jobs too?
33. Do the home nurses have any pension/ welfare schemes/ insurance? (at least the registered agencies)
34. In a month, how many holidays are provided for the employees?
35. How long do you provide a home nurse for a particular client? If they need the services for the long run, do you replace the home nurse with another after a specific period?
36. What are the terms and conditions concerning your services? Explain how you regulate the home nurse-client/client's family relationships.

Appendix 3: Schedule for the Home Care Clients

PERSONAL DETAILS

Informant ID

- ❖ Patient's Name/ pseudonym:
- ❖ Patient's Age:
- ❖ Patient's Gender:
- ❖ Patient's Illness:
- ❖ Caste/ Community affiliation:
- ❖ Duration of the home nursing contract in months or years:
- ❖ The number of Home Nurses (HNs) hired during the period:

Questions related to family

- ❖ Respondent's relationship with the patient:
- ❖ Does the respondent co-reside with the patient? Yes/ No
- ❖ Who was the patient's primary caregiver before the home nurse was hired?
- ❖ Is the primary caregiver employed?
- ❖ Purpose of hiring the HN: Assistance with daily activities/ to carry out healthcare needs/ to provide emotional support (or a combination of these)
- ❖ Does the HN help you with household chores? Or only take care of the patient's needs?
- ❖ Did the patient's family members provide support to the HN? Or, did the HN singlehandedly provide care?

Questions on the employment

1. Did you seek the home nurse through a home nursing agency?
2. Were you able to choose from some people available with the agency, or were you allotted one by them?
3. If not, how did you find the home nurse? (through social networks? Suggested by any medical personnel?)
4. Do hospitals make referrals, i.e., contact particular nursing agencies if there is a need for private nursing care? Any other referrals adopted by you with regard to employing the nurses?
5. What were the criteria employed to select the home nurse?
 - a) Gender and age of the home nurse?
 - b) Educational Qualification – do/did you prefer academically qualified personnel?
 - c) Physical fitness/ physique of the home nurse?
 - d) Physical appearance?
 - e) Caste (Did you want a home nurse from the same caste/ community as yours? Did you not want to employ someone from a particular caste/ community like SC/ST or Muslim?)
 - f) Family background
 - g) Marital status (did you prefer a widowed/ divorced/ unmarried person or a married person?)
 - h) Acquaintance with the person or connection via social network

- i) Culinary skills of the home nurse (in those cases where the home nurse is employed to take care of household tasks too)
 - j) Caring nature and kind behaviour of the home nurse
 - k) Any other?
6. Why was it decided to hire a home nurse? (Reasons- family members busy with their work, even the women in the house are working/ employed, challenging for the kin to handle the patient or any other reason)
7. Why was it decided to give home-based care? Please choose any of the reasons
- a) illness is not that severe to hospitalise the patient,
 - b) hospital-based care is expensive,
 - c) home is more than a place; it is a feeling,
 - d) family members can be in touch with the patient,
 - e) the patient can be more comfortable since it is own home,
 - f) not happy with hospital settings and hospital staff, do not like the power relations in the hospital setting and authoritative behaviour of hospital staff, etc.
 - g) Any other?
8. What significant differences do you find between hospital staff nurses and home nurses (besides the former being academically qualified)? (home nurses are less bossy, we can be at ease since it is home, home nurses are more close, approachable, friendly and attached to the patient and other family members, etc.)

9. If the patient is an elderly parent, where do you want them to spend their last days? If you prefer the death to occur at home, is it also one of the reasons for arranging home-based care?

10. What do you think are the probable drawbacks of not providing hospital-based care? (since mostly the home nurses are not qualified personnel)

11. Why were you ready to provide home-based care given by an unqualified person and, in a way, risk the life and health of the patient?

(Choose any of the reasons- patient's illness is not that severe, cheaper than hospital-based care, comfort and a feeling of belonging at home, the patient is anyway nearing death, home nurses also have received some training on nursing tasks, etc.)

12. Did you try searching for competent and well-equipped personnel to look after the patient? (If not, why? – Qualified personnel are unavailable, hiring them is more expensive, their behaviour/ attitude is not favoured, etc.)

13. When it was decided to hire a home nurse, was the patient consulted, i.e., their opinion taken into account? (In case the patient is not too frail/weak to decide or express an opinion)

14. Were your close relatives informed when you decided to hire a home nurse? Or, did you try taking their help for the patient's care before employing the HN?

15. How co-operative is the patient in the caregiving process? Co-operative/ Neutral/ Non-cooperative

16. How good is the rapport between the home nurse and the patient? Do you ever leave the patient alone with the nurse and go somewhere? (This can also indicate the level of trust the client's family has in the home nurse)

17. How much is/ was the HN's monthly salary?

18. When you decided to employ the home nurse, did you initially want them to do tasks other than the patient's care, i.e., household chores? Or, did the HN volunteer to help your family with the household tasks?

About the services

19. How satisfied are you with the HN's services? (Very satisfied, satisfied, moderate satisfaction, dissatisfied, extremely dissatisfied)

20. If you are dissatisfied, what are the primary reasons?

21. If you are satisfied, what are the reasons?

22. Do theft cases often happen under the mask of home nursing services? Have you experienced any such incidence?

23. Have you had any other bad experiences with any home nurse you employed? (anything such as a fight, theft case, bad behaviour of the HN, etc.)

24. What is your family type? Nuclear or joint

25. If it is a nuclear family, do you think you wouldn't have hired a home nurse had your family type been a joint one? Or, has the home nursing service become essential in today's times because the family members are employed formally?

26. Do you think that the weakening family ties and relations have, in a way, resulted in the mushrooming of home-based nursing service providers and such agencies?

27. How do you expect the nurse to behave with the patient and your family? Friendly (like a family member) or formally (just like an employee)?
28. Do you feel that the home nurse helped improve the patient's condition, OR how far has the home nurse helped the patient cope with the disease?
29. Did you ever feel that the home nurse's presence had been able to positively impact the patient's life and health? (Because often the patient's kin/ relatives are not present, the nurse's presence might help the patient fight loneliness)
30. How close is the home nurse with the patient and the family members/clients? Do you all sit together and have food? Or does the home nurse have food separately?
31. Did the home nurse remain in contact with you even after the contract ceased? (for those who had employed one earlier)
32. Did you ever terminate the employment of any HN due to misconduct?
33. If you need a home nurse's help for the second time, will you contact the nursing agency and ask for an HN you hired earlier?
34. What are the popular perceptions about home nurses? Who are they, and why do they get into this job? Choose an option
- ❖ People who are majorly from economically poor backgrounds or broken families (widows/ divorcees)
 - ❖ People who joined this field because they couldn't find other jobs
 - ❖ People who are genuinely interested in caring for patients

- ❖ People who are ready to do anything for money (including theft or involve in illicit relationships)
- ❖ Any other?

35. What is one drawback of the home nursing industry/ home nurses in general?

- ❖ Not all are committed/ sincere in the job
- ❖ Not all HNs are trained in health care tasks
- ❖ Ill-treatment of patients
- ❖ Interference in personal matters of clients/ privacy issue
- ❖ Theft issues
- ❖ They do not adjust with client family members
- ❖ Excessive phone usage
- ❖ Many HNs have weak moral characters
- ❖ Nothing as such
- ❖ Any Other?

36. What is one plus point you find about the home nursing industry/ home nurses in general?

- ❖ Caring and loving attitude towards patients
- ❖ A helping hand for working women
- ❖ A trustworthy HN is an asset- can leave patient and home with them
- ❖ Help in household chores
- ❖ Behave like a family member/ relative
- ❖ HNs perform all tasks without any inhibition
- ❖ Any other?

37. Who, according to you, is a Home Nurse?

- ❖ Anyone who can care for the patient's personal care needs (bathing, feeding, toileting etc.)
- ❖ Anyone who can care for the patient's personal care + health care needs (giving medications, carrying out medical care/ nursing procedures)

38. Should HNs perform healthcare/ medically oriented nursing tasks?

- ❖ Yes, desirable
- ❖ Yes, mandatory
- ❖ No

39. Should HNs perform household tasks?

- ❖ Yes, desirable
- ❖ Yes, mandatory
- ❖ No
- ❖ According to the HN's wish

40. How far do you think the label '**Home Nurse**' suits these caregivers?

- ❖ Very well
- ❖ To an extent
- ❖ Doesn't suit at all the people- Suits those who can perform health care tasks
- ❖ Some other terms like caregiver/ helper suits better

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In the Pursuit of an Identity: Analysing the Case of Male Health Care Providers

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In the Pursuit of an Identity: Analysing the Case of Male Health Care Providers

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Abstract

Being a female-concentrated job, nursing has forgotten the place of men within the profession despite their contribution since time immemorial. The heightened efforts of Florence Nightingale to transform nursing into a respectable female occupation denied men the opportunity to enter this domain. Despite their growing representation, they are still a minority in nursing in countries across the globe. When the occupational roles do not conform to the gender-appropriate roles prescribed by the society, the 'male' nurses' prestige and self-esteem are at risk since others recognize them neither as true nurses nor as real men. Drawing majorly from secondary sources and data gathered from an anthropological study of in-home care providers in the South Indian state of Kerala, this paper on the predicament of men in nursing throws light on the 'spoiled identity' they carry; the work stress, gender stereotyping, stigma and discrimination they encounter by always being suspected and their very identity and sexual orientation questioned. A note on the strategies employed by them to overcome the problems is also within the purview of this paper.

Keywords: nursing, profession, male nurses, care providers, identity

En Busca de una Identidad: Analizando el Caso de los Proveedores de Cuidados de Salud Masculinos

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Resumen

Al ser este un trabajo realizado principalmente por mujeres, la enfermería ha olvidado el lugar de los hombres dentro de la profesión a pesar de su contribución desde tiempos inmemoriales. Los intensos esfuerzos de Florence Nightingale para transformar la enfermería en una ocupación femenina respetable le negó a los hombres la oportunidad de ingresar a este campo. Aunque el número de hombres que ingresan a la profesión ha aumentado con los años, todavía se mantienen como una minoría en el campo de enfermería en países de todo el mundo. Cuando los roles ocupacionales no se ajustan a los roles apropiados para el género prescritos por la sociedad, el prestigio y la autoestima de los estos enfermeros se encuentran en riesgo ya que otros no los reconocen como verdaderos enfermeros ni como verdaderos hombres. Basándose principalmente en fuentes y datos secundarios recopilados de un estudio antropológico de proveedores de atención domiciliaria en el estado de Kerala, en el sur de India, este documento sobre la situación de los hombres en el campo de enfermería arroja luz sobre la "deteriorada identidad" que llevan consigo; el estrés laboral, los estereotipos de género, el estigma y la discriminación que enfrentan al ser siempre sospechosos y su identidad y orientación sexual cuestionadas. También se encuentra una nota sobre las estrategias empleadas por ellos para superar los problemas dentro del ámbito de este documento.

Palabras clave: enfermería, profesión, enfermeras, proveedor de cuidados, identidad

Nursing, perceived to be a profession meant for women then and now, is a field that largely retains the characteristic of female domination across the globe. Any discussion on the profession of nursing would remain incomplete without a mention of the efforts of Florence Nightingale whose brainchild was to transform nursing into a respectable female occupation. When feminine qualities found parallels with attributes of a nurse, doors to enter the profession were closed for men. Women who are naturally considered as caregivers became the suitable members to perform the role of nurses thereby rendering nursing the tag of a more or less single-sex occupation. Landivar (2013) identified an ascent in the number of males in the US registered nurse force since the 1970s, yet they remained a modest 11 percent in 2011 (as cited in Cottingham, 2019, p.198). Purnell (2007) demonstrated a worldwide point of view where men comprise less than 10% of the nursing workforce in China, Denmark, Finland, Hungary, Australia, Mexico, and New Zealand. Few men seemed to become nurses in Pakistan and Arab Middle-Eastern countries. Italy, Spain, and Portugal had about 20% of men as nurses when England and Israel had slightly fewer men in the profession. Male nurses in the Czech Republic and Francophone Africa displayed greater numbers and men outnumbered women in the latter. Bernabeu-Mestre, Carrillo-García, Galiana-Sánchez, García-Paramio, & Trescastro-López (2013) find that “women represent more than 80% of nursing professionals in Spain” (p. 288). Ayala, Holmqvist, Messing, & Browne (2014) report that only 6-10 percent of nurses in Chile are men, according to 2013 statistics available (p.1481). Aspiazu (2017) states that “in 2016, 85% of nurses in Argentina were women” (p.11).

These numbers do not lie. However, contrary to what is imagined, Mackintosh (1997) claims that “men’s contribution has been perceived as negligible due to the 19th-century female nursing movement has had on the occupation’s historical ideology” (p.232). The historical backdrop of nursing has more or less entirely neglected the role of men despite their involvement as caregivers in asylums, army, etc. Many scholars have similar findings: Men have played a dominant role in organized nursing dating back to 330 A.D. in the Byzantine Empire. During this era, hospitals were one of the major institutions where nursing emerged as a separate occupation, primarily for

men (Bullough, 1994). Moreover, military, religious, and lay orders of men known as nurses have a long history of caring for the sick and injured during the Crusades in the 11th century (MacPhail, 1996). In the United States, men served as nurses during the Civil War. John Simon, the lesser-known rival of Florence Nightingale, was the founder of an experimental field hospital in Germany during the Franco-Prussian War (1870-1871). Male nurses were hired to staff the hospital, and mortality rates among the troops were kept abnormally low (Halloran & Welton, 1994). (Meadus, 2000, p.6)

These works attempted to highlight that nursing is not a field alien to men though women have established kind of a monopoly over it since the last few centuries. In the mid-20th century, nursing witnessed a drastic change in the gender composition of its workforce. The research by Ramacciotti and Valobra (2017) and Ramacciotti (2020) reveal that the history of nursing in Argentina saw a state-sponsored feminization of the profession. The efforts of the Eva Perón Foundation in this direction are mentioned by the authors. They point out that “the nursing schools reinforced this discourse that accentuated the feminization process and made the role of males invisible” (Ramacciotti & Valobra, 2017, p.382). Though male entry was restricted by several nursing schools, it was not uniform. The authors provided instances of nursing schools that did not discriminate against men. The Red Cross School of Nurses in Santa Fe, the Ministry of Health of the Province of Buenos Aires’ school for paratroopers, etc. were among them. “The 1944 San Juan earthquake in Argentina is also considered a landmark event that attracted many women to join nursing” (Ramacciotti, 2020, p.48). Ramacciotti does not forget to mention how female pioneers in healthcare in the country (who were influenced by the system created by Florence Nightingale) found nursing an ideal occupation for women. “Cecilia Grierson’s efforts to professionalize nursing seem to have resulted in its feminization” (Ramacciotti, 2020, p.62). Studies also demonstrate the association of gender and caregiving, and the tendency to replicate the sexual division of labor in the private sphere into the public sphere. Gill (2018) identifies this “gendered construction of the occupational realms” in the Indian context (p.44). Ramacciotti (2020) also shares a similar view when she says “women occupied jobs in which they

displayed that supposed feminine nature” since they were efficient in those tasks (p.36).

It is also true that nursing as a profession does not enjoy a great status; nurses’ subservient position compared to doctors is particularly remarkable. Nurses were considered as lacking in skill and there had been a dishonour attached to nursing prevalent in the country. Nurses have many times been questioned of their character since they involve in intimate body-care, interact with men, work during night hours, and deal with polluting substances (Abraham 2004; French, Watters & Matthews, 1994; Hollup, 2014; Nair & Healey 2008; Percot 2006; Varghese & Rajan 2011). Authors like Etzioni (1969) have classified nursing in the category of semi-professions, along with teaching and social work. Yet, nursing had not received due respect until recently in a developing country like India (Gill, 2018).

A transformation in this scenario began to occur due to globalization and the increased demand for nurses overseas. Indian nurses who have been migrating internationally witnessed respect for their profession and improved working conditions which paved way for their economic security (George 2005; Nair & Healey, 2008; Percot 2006). Even though the major motive behind migrating was financial independence, overseas migration not only helped the nurses fetch themselves enhanced earnings but also became the reason for many to select nursing as a vocation back in their homeland. More nurses became sought after in the marriage market and a preference for nurses working abroad was observed (Percot, 2006a).

The better prospects that migration offered were able to attract a lot of men to enter the field and various studies reported an upsurge in nursing becoming a career alternative for men in the last few decades (Buerhaus, Staiger, & Auerbach 2004; Hodges et al., 2017; Trossman, 2003; Walton-Roberts, 2010; Zamanzadeh et al., 2013). However, they are still negligible and a nation-wide analysis of the nursing institutions in many countries would testify this. Predominantly, female occupations are thought to be less professional compared to male-dominated ones and various scholars adhere to the fact that gender acts as an obstacle to professional advancement. Gilbert and Rossman (1992) opine that this happens since “women are viewed from a gender perspective as less able to take on leadership roles” (p.234). The situations of

men who go into female- concentrated professions have to be looked at from various angles. This paper majorly focuses on the difficulties, as well as benefits the ‘male’ nurses experience due to being in this field. The gender bias and discrimination ‘male’ nurses are subjected to for doing the ‘women’s work’ has also been highlighted.

The Two Conjectures About Male Nurses and The Issue of Identity

Certain professions are considered appropriate for women, the oft-cited ones among these being teaching and nursing. Meanwhile, women had not limited themselves and remained restricted to those realms that are thought to be apt for them. They have been entering previously male-dominated professions and have become doctors, lawyers, and businesswomen. Though their journeys were hard, many scholars opine that women received much more support and encouragement compared to men who enter female-concentrated jobs like nursing. The belief that nursing is an arena meant for women remained even after men re-entered the vocation, thereby leading Mackintosh (1997) to produce the assumptions “that the introduction of male nurses was an attempt in some way to violate the respectability of the occupation and male nurses could therefore not be “real” men since men were not naturally capable of performing caring activities” (p.235).

These two conjectures have to be analyzed critically since these statements are a threat to the identity of the male nurses in particular and men in general. Since a profession is seen naturally suitable for a particular gender it does not mean that the entry of another gender into it would make it less respectable or irreverent.

Men’s Entry: Boon or Bane?

The world has been witnessing the interplay between gender and division of labor due to which occupational sex-typing prevails. Elliot (2016) suggests that “the central features of caring masculinities are their rejection of domination and their integration of values of care, such as positive emotion,

interdependence, and relationality into masculine identities” (p.241). In a system where men are favoured, those occupations labelled traditionally male have had an upper hand. Evans (1997) proposes that “in female-dominated occupations such as nursing, patriarchal gender relations function and due to this male nurses tend towards powerful and authoritarian positions” (p.226).

A few authors have found that nursing has been a profitable game for men who chose it as a career. Lupton (2006) identifies three main phenomena and writes that:

Firstly, men progress more quickly than women to senior positions - riding the ‘glass escalator’ (Williams, 1995). Secondly, men may be channelled into particular specialities in occupations that are regarded (by themselves and by others) as more appropriate to their gender, and that often carry greater rewards and prestige-which may be both a cause and a consequence of their gender associations. The third advantage relates to remuneration. Williams (1995) and England and Herbert (1993) have shown that men are paid more than women in female-concentrated occupations. (pp.105-106)

Though men have had these obvious advantages concerning remuneration and placement in elite/ superior positions, many difficulties are involved in the process. Heikes (1991) puts forth the idea that:

Male nurses, like other tokens, experience stress at work due to their token status and tend to experience conflict in the work setting because of incompatible gender socialization. The very traits which help males in other occupations- ambition, assertiveness, and strength-create stress and friction for the male which may hinder them occupationally. In addition to work-related stressors, they must cope daily with the consequences of being a man doing “women’s work”. (p.398)

“Cockburn has suggested that the handful of men who cross into traditional female areas of work at the female level will be written off as effeminate, tolerated as eccentrics or failures. (1988, p. 40)” (as cited in Lupton, 2006, p.106). Simpson (2004) studied masculinity at work and noted that “emotional labour such as teaching, nursing, and social work may call for special abilities that only women are deemed to possess (Hochschild, 1983)”. This can “invite challenges to men’s sexuality and masculinity if they adopt a more feminine approach” (Simpson, 2004, p.7)

Another well-documented theme is that of role strain¹. Stott (2004) identifies that “males tended to choose “less intimate” specialization areas such as administration, anesthetics, and psychiatric nursing to cope with role strain in a female-dominated profession. (p.92). She also comments that “the male nurses perceived themselves as being the victims of discrimination” (p.92). “Issues such as role strain, minority status, and stereotypical attitudes are perceived as being central to the unique conflicts facing men in nursing”. (Stott, 2004, p.95)

Do Men Get Support to Enter Female-Concentrated Professions?

According to Egeland and Brown (1988), “males appear to encounter more negative criticism from the public on entering female-identified occupations. For example, they are “held suspect” and penalized for role violation” (as cited in Meadus, 2000, p.6). These men encounter a lot of hardships and are subjected to criticism and ridicule since they challenge the conventional image that nursing has (Villeneuve, 1994; Williams, 1992). Meadus (2000) notes that “another commonly held stereotype concerning men who choose nursing as a career is that they are effeminate or gay (Boughn, 1994; Gray et al., 1996; Williams, 1992; Williams, 1995)” (p.8). “The stigma associated with homosexuality exposes male nurses to homophobia in the workplace”. (Harding, 2007, p.636). In the opinion of Mangan (1994), the labelling of male nurses as effeminate or homosexual can be interpreted as a social control mechanism that redefines nursing as a woman’s work” (as cited in Meadus, 2000, p.9). Segal (1962) elucidates that “male nurses are suspect because they enter a traditionally female occupation. They are involved in a status contradiction between characteristics ascribed to men in our society and characteristics that are supposed to inhere among members of the nursing profession” (p.37).

Since the perception that female-oriented jobs are easy to perform exists, many a time the male nurses are regarded as lacking skills to perform male-oriented professions. They are also categorized as lazy by some since they choose female-dominated jobs that demand less effort and physical strength.

Citing Macintosh (1997), Anthony (2004) asserts that “when the nursing profession perpetuates the feminine stereotype and uncritically uses a feminine language and value system, individuals who do not fit that stereotype are at risk for being oppressed and silenced by those who do fit the image” (p.123). It is not just in the workplace that male nurses encounter these difficulties and suffering. During their education as well, male students are likely to suffer from these issues and barriers such as “the feminine paradigm in nursing education, a lack of role models and isolation, gender-biased language, differential treatment, different styles of communication, and issues of touch and caring” (O’Lynn, 2007, p.174).

It has been accentuated by Evans (1997) that male nurses employ “strategies that allow them to distance themselves from female colleagues and the quintessential feminine image of nursing itself, as a prerequisite to elevating their prestige and power” (p.226). The gender-specific specializations whereby male nurses are involved in selecting the more ‘masculine’ elements have been analyzed already. Such specialties include psychiatry, anaesthesiology, emergency care, etc.

Significance of the Study

As far as the Indian scenario is concerned, the literature suggests that the country has produced umpteen nurses and has been a supplier of nursing care services worldwide. The greater part of these studies on nursing has had hospital-based nursing as the focus. A handful of entries has looked at home-based nursing care as research conducted in India has mainly concentrated on nursing homes, community nursing, and palliative care. Indian nurses have migrated internationally and a lion’s share of them have been nurses from Kerala, “the leading Indian state for the training and ‘export’ of nurses for the international market” (Walton Roberts & Rajan, 2013, Introduction, para 3). ‘Home nursing’ (home-based nursing) has become a buzzword in the arena of nursing care in Kerala over the last few decades. The care providers stay with the patients in the latter’s homes and deliver their caregiving services. Though some studies like the one by George and Bhatti (2019) have focused on male nurses who work in hospitals in Kerala, there has been no scholarly effort to

look into the cases of men who work as in-home care providers. The need for in-depth studies on home-based care and live-in care providers prompted the researcher to undertake the study with the aid of an anthropological perspective and methodology.

Methodology

The data for the study were collected from May 2018 to July 2019 from three categories of people who formed the part of the study viz. the care providers, owners of nursing agencies who supply the care providers, and customers who avail the services to take care of patients. The area chosen for the study was the districts from Southern Kerala where the home-based care industry is more in prevalence. Thiruvananthapuram, Kollam, Pathanamthitta, Alappuzha, Kottayam, and Ernakulam were these districts. In-depth interviews of the respondents with the aid of a semi-structured schedule were conducted. The face-to-face interviews lasted for 55 minutes on average. The nursing agencies which the participants were associated with served as the sampling frame. Since the number of men working for an agency is less, the snowball technique had to be applied to reach a desirable sample size.

The data presented in this paper consider the cases of 20 male care providers who were a part of the study that had a total sample of 150 care providers. The interviews were conducted in the regional language (Malayalam) and were not tape-recorded. The anonymity of the respondents was assured and their informed consent sought. The interview schedule initially framed in English was later translated to Malayalam for convenience. The respondents were asked questions about their reasons and motivations behind taking up the job, their prior work experiences, their relationship with the patients, and the pros and cons of this non-traditional occupational choice. They were also asked to briefly narrate their experiences in the field.

Results

Previous Employment and Prior Work Experiences

The twenty men were aged between 32 and 70 ($M = 48.05$ years, $SD = 11.44$). Their experience in the job ranged from a few years to about two decades ($M = 7.7$ years, $SD = 4.76$). Though only four of the men were academic nursing qualified, five others have had prior experience as hospital staff like nursing attendants and aides. Low pay and difficult working conditions were the two main reasons why these people left hospital-based work. 55 percent of the sample has taken nursing training from the private nursing agencies that they are associated with. The nursing trained participants also include five people who were trained under the Indian Red Cross Society and thus guided by hospital nurses. Most of the respondents perform health care tasks like insulin administration, monitoring blood pressure, catheter care, nasogastric tube feeding, etc.

Reasons for Becoming a Male Caregiver

An inquiry into the rationale for taking up the job revealed that eight men were influenced by their relatives and friends. The wives of four out of these eight people also worked as in-home care providers and were the ones who motivated their spouses to take up the job. When four participants opined that they found the job satisfying and rewarding, five people expressed a desire to help people since they considered serving the sick as a divine activity. Nine participants mentioned that this job paid them better than their previous occupations. For them, better pay has been a motivating factor in addition to the interest they had to take care of patients. However, it could be known that this was never a first-choice occupation for any of the study participants.

Thomas recalls, 'My wife has been working in the field since 2007 and she persuaded me to join the same nursing agency she was working for. After I got in, I realized that I love to care for the elderly. I am not in this job just to earn money; I want to make a change in the lives of people. My previous job used to pay me better but here I find myself more satisfied when I serve the

ailing and needy. I think I should thank my wife for leading me to this job'. John discerns, 'It needs a lot of patience and will power to be in the profession of nursing. It is never an easy job for men to do this since we have not done the caring work at our homes. But one thing for sure is that caring for the sick is a divine activity. My parents are happy about the good work I am doing by helping those in need. It was my elder sister (a hospital nurse) who, from my school days, has inspired me by telling the stories of nurses who did the caring when doctors did the curing. But nursing was not my first choice of occupation. When I wanted a change from my previous job, I thought why not give home-based care a try. And here I am'.

Perceptions About Nursing and Caregivers

Out of the 20 participants, six either considered caregiving as a women's job or thought it is perceived so by society. The rest voiced the idea that they were comfortable working in a female-dominated sector and that men are also equally capable of providing care to the ailing. Some respondents believe that as long as they look after male patients alone, there is nothing to feel ashamed about. Nevertheless, only a quarter of the participants have revealed their occupational identity to all of their relatives and friends. When 12 men made their family members aware of their job, three kept it hidden even from their close kin. Out of these 17 who let their family members informed about the job, six said that their family members were very supportive. The rest pointed out that their families had mixed opinions about them doing the job. A major reason why men had to hide their work identity was to not disclose their involvement in home-based work. They were afraid of the humiliation they might have to suffer if their relatives and friends know that they are doing 'women's work'. It is this fear that led 14 of the participants to disguise themselves to be working as hotel cooks, shopkeepers, security personnel, and teachers. Most of them worked in other districts and did not like to work near their hometowns. This confirms the fact that many men often do not get enough social support to perform their roles as care providers.

When they were criticized and ridiculed for their choice of job, some care providers sought solace in the words of their male co-workers, and relatives who performed similar work. Michael states, ‘I am not alone, my brother-in-law also works as a home-based caregiver. I also have a few friends who do the same job. I used to be a nurse at a private hospital. I left the job since I had difficulties with the work conditions. Later, I went abroad in search of a better life but I had to return to Kerala due to personal reasons. After a couple of years, I took up this job. Even if others believe that this is a small job, for me it is a big deal. It is this job that fetches my bread and butter now and I am well pleased with it’. Harry, who dropped his job as a hospital nurse also has a comparable opinion and thus says, ‘my uncle and friends who are home nurses have been my support system. Even when my wife’s family asked me to quit the job and find another one, they stood by me and supported my decision to continue in the job’. Some men in the study had to choose the job at the cost of losing their prestige. In such cases, the desire to help people and work satisfaction were the pull factors (besides better pay than the previous job).

Problems Facing Male Caregivers

Five men recalled instances of physical or mental harassment they had experienced from the patient/ patient’s relatives. It was mostly the patients who physically assaulted their care providers out of their anger and frustration. But the caregivers understand the helpless conditions of the patients and adjust with them. Three participants pointed out how the labels of ‘gay men’/ ‘homosexual’ haunt the men in the caregiving profession and one respondent recollected an incident where he was approached by a patient’s relative since he was mistaken for a gay man.

The participants were asked if their gender restricted them from performing their roles as care providers. Though some of them believe that the provision of care is women’s job and thus the work performed by male care providers are stigmatized, eight men stated that it does not matter since they do not take care of patients of the opposite sex. A few reinstated that the job still lacks respect in our society. However, none of the respondents opined

that they find any aspect of their work polluting- whether it be bathing or toileting the patient. It is also worth noting that none of them expressed dissatisfaction with the job though they have various inconsequential difficulties due to staying away from their families.

There still prevails a stigma around nursing and the study participants reveal that it is worse when it comes to home-based nursing. Men who perform non-traditional occupations could have a sense of shame when they do not live up to social expectations. Adam comments, ‘People think that we are unqualified and good for nothing since we are in-home care providers. This makes me sad because many people like me are trained in healthcare tasks. I have not disclosed my occupational identity to my relatives since they believe it is unmanly to involve in home-based care work. They will tell you that men are meant to work outside homes and not inside.’ John also has a similar opinion on the societal perception of home-based caregivers. He says that ‘Some people have asked me why I go for a job where I have to clean people’s dirt and fecal matter. I was told that it’s better to work in a tea shop or a hotel’. John hypothesizes that even if nurses are academically qualified personnel, they are equated to servants or cleaning staff. He laments that society doesn’t recognize the good work caregivers are doing. Jacob mentions that ‘Not just women, but men in this field are also prone to harassment and moral policing. We men are considered as homosexuals. People call us ‘Chanthupottu’ (A term which became popular in Kerala after a Malayalam movie of the same name and is used by some people in the state to refer to homosexual or effeminate type men). Even now, caregiving does not have a good reputation in our society’. George finds that ‘Men in this job find it difficult to get marriage alliances. A male home nurse is often portrayed as a gay man’. He also adds that ‘Our society perceives that being homebound is not something meant for men and it is due to this reason that most of us do not reveal our job identities. I’d rather like to work as a hospital nurse; I think that has a better acceptance in our society.’

Relationship with Patients and Work Satisfaction

When their family members and relatives did not take proper care of elderly patients (due to various reasons), paid care providers came to their rescue. They have been a tower of strength for the sick elderly as they sustain the lives of the patients by providing emotional support in addition to physical tending. Francis describes, ‘It feels good to be in this job since there is a homely atmosphere in the patient’s house. I take care of an 87-year- old man who broke his leg recently. I don’t know how long he will survive. I consider him like my grandfather. His children are busy with work and they do not spend enough time with him. He enjoys my company and I often crack jokes to make him laugh. I feel happy when I see him smile’. Vijay is of the view that one has to be a good listener when involved in elderly patient care. He says, ‘Many times the adult children do not have time to listen to what their elderly parents have to say. Then, it is the care providers who have to lend their ears to the stories of elderly patients. This will help develop bonding and attachment between the two and might also help improve the health condition of the patient’.

Strategies Employed to Sustain in the Field

In India, even if they enter female-dominated occupations, the majority of men try to make sure that they conform to the mainstream / traditional masculine values. This is in contrast to the study undertaken by Bodoque-Puerta et al. (2019) in Spain which found that the male social caregivers “distance themselves from the values of traditional masculinity to construct an alternative masculinity” (p.220). It was observed that the male care providers consider knowledge to perform physiotherapy as something that would give them an upper hand compared to their female counterparts.

The study participants consider being able to perform physiotherapy as a desirable qualification for male care providers. 12 out of the 20 participants have done physiotherapy courses and 5 men have learned the basics of the same through experience in the field over the years. This aspect is akin to male nurses concentrating on specializations like psychiatric nursing that appears to be a specialty that helps them display their masculine qualities. Most of the

participants also mentioned that they do not involve in performing any household tasks at the patient's home unless they work for elderly patients who do not have any co-resident relatives. This is in contrast to the female care providers who often help with the household chores though they are employed for patient's healthcare. The respondents highlighted the fact that they see to it that they maintain the 'clean habits' like abstaining from alcohol consumption and smoking since these are considered pre-requisites to enter the field and remain in the job.

Does a Glass Escalator Exist?

A feature of 'glass escalator' (Williams,1992) that is observed in this study is the gender-wage gap. Female care providers formed the majority of the larger study. Compared to them, the male care providers earned about 2000 rupees more. The average monthly salary of the men is around 16000 rupees (~225 USD) and thus approximately 15-20 percent more than that of women. According to the nursing agency owners, this wage gap exists because taking care of male patients is riskier and more difficult. When asked about their opinion on the wage gap and why they thought men out-earned women, half of the respondents felt that since it happens in other jobs, the same is replicated in this job too. The other half believed that they are paid more as it is tougher to take care of male patients and therefore to retain male care providers in the job, they should have better pay than their female co-workers. Despite this being the case, most of the respondents mentioned that their work is harder than that of their female colleagues.

It could also be noticed that when choosing an employee, clients were particular about habits such as smoking and alcohol consumption of male care providers. They do not wish to employ men who could be a threat to the safety of the female family members. John remarks, 'I do not consume alcohol or smoke cigars. I have always behaved well with everyone I have worked for. I think teetotallers are better liked by patients' families. Though this is the case, bachelors like me find it difficult to make it into this field because we are held suspect for various reasons'. Unlike hospital-based nurses, in-home care

providers do not have any benefits and job promotions/ advancements in their positions. Since the employees carry the same job title irrespective of gender, it cannot be completely categorized as an instance of a glass escalator. Moreover, some of the above narratives demonstrate the difficulty that men (especially, unmarried men) experience to gain entry to the field and to sustain in it. As male care providers are employed only for patients of the same gender, they do not pose a threat to the opportunities of the womenfolk.

Discussion

This study complements the prior research on men in nursing by considering the cases of a few men in home-based care services from the state of Kerala in South India. The efforts of male nurses towards the profession have not been adequately recognized though they have been actively involved in caring and nursing people. Due to scrutiny and suspicion that arise when men enter nursing, several men identified a split in terms of how they presented themselves at work and outside work. Some do not like to be known as nurses when they are in the social context since their tags as ‘male’ nurses often go against the desirable notions. It is also worth noting that a non-gendered occupational title can have a positive effect on societal perceptions. “In Mauritius, the professional title and grade ‘nursing officer’ is non-gendered and thus does not represent a barrier to men” (Hollup, 2014, p.758). On the contrary, some of the study participants from Kerala consider the term ‘home nurse’ to suit female caregivers more than males.

Studies have reflected that while most men expressed higher levels of satisfaction with their career, role strain is inescapable. Participants in the present study also expressed similar views and tensions related to the public perceptions of men performing caring work and the indifferent attitudes of people around them. But they believe that as long as they look after male patients alone, there is nothing to feel ashamed about. They also highlight the fact they work as per the care plan and do not cross the boundaries to help their clients in domestic chores (unlike the female caregivers who go the extra mile). In their study on male nurses from Kerala, George and Bhatti (2019) find that “nursing is not perceived suitable for men and the majority of the

participants complained about the difficulties in convincing their families or being ridiculed by their friends” (p.121). The respondents of the current study had similar opinions though not all of them consider the job as women’s forte. However, it sheds light on men performing home-based care being prone to double stigma: for taking up nursing, a women’s job and for working at home, a sphere meant for women. Likewise, Acker (1990) highlighted the gendering of occupations and workplaces (cited by Scrinzi, 2010, p.46).

Prior research on men in nursing highlighted men’s choice of specialism and its association with career progression. Male caregivers in Kerala also showed an interest in one special area- the ability to perform physiotherapy and they take pride in being able to perform the task. However, this does not contribute to career progression. An effort made to analyze the presence of a glass escalator as experienced by the study participants shows that there are no real ‘hidden advantages’ (Williams, 1992) that they have over female caregivers.

It was observed that support from significant others was a persuasive factor in occupational selection. Zamanzadeh et al. (2013) came up with parallel findings from their study of male nurses and the authors add that “most of this support comes from females who are close to men that are interested in pursuing a nursing profession” (p.53) This has been true to an extent in the current study. However, unlike their study that found career opportunities and salary as the most important motivators for entrance (Zamanzadeh et al., 2013, p.53), this study shows that desire to help people and satisfaction derived from the job have also been more important motivators for the male nurses. According to Araüna et al. (2018), the ability to use and maintain a sense of humor in critical situations has been identified as a characteristic of male nurses. The caregivers in the study also exhibited similar conduct. Dill et al. (2016) in an analysis of a ‘wage penalty’ find that “men who are involved in direct care work occupations experience a penalty for caring” (p.354). However, the participants in the present study do not perceive the existence of such a penalty. The narratives provided above exemplify that the wages they earn are satisfactory and a considerable proportion of the sample find it better compared to that of their previous occupations.

Conclusion

The paper aimed to analyze male in-home care providers' reasons and motivations behind taking up the job, their prior work experiences, their relationship with the clients/ patients, and the perceived pros and cons of this non-traditional occupational choice. The study from the Indian state had male caregivers comprising only 13.33% of the total sample. The situation is not different in other states of the country. It is identified that home-based care is also female-concentrated, akin to hospital-based nursing. Authors like Ayala et al. (2014) consider the entry of men in substantial numbers to benefit the future of nursing as they assume that "the masculine presence could counterbalance an alleged lack of political power" (p.1483). But, the authors caution that this move "may lead to the reproduction of earlier historical inequalities if not handled judiciously" (Ayala et al., 2014, p.1484). Although Shen-Miller and Smiler (2015) opine the possibility of an overall rise in wages in the field as a result of men's substantial entry, a remark is also made about a subsequent gender-wage gap that could occur (p.272). In a similar line, Bernabeu-Mestre et al. (2013) opine that the inclusion of more men into nursing should not be at the cost of compromising equality in terms of responsibility and power (p. 288). However, the current study participants do not reflect the presence of a glass escalator, barring the aspect of the gender-wage gap.

As several authors consider male (re)entry to nursing as a much welcome move, multiple interpretations have come up from various studies that were conducted globally. "The presence of men in feminized occupations can challenge the sex-typing that characterize them" (Scrinzi, 2010, p.59). "It is anticipated that a large influx of men will raise the profession's status and prestige" (Evans, 1997, p.227). Elliott (2015) mentions the need to encourage men to engage in gender-equal and caring practices. (p. 247). Research by Aranda et al. (2015, p. 105) comes up with similar findings and argues that the inclusion of men "could produce a change in gender stereotypes". Dill et al. (2016) are also optimistic that "the presence of men in low- and middle-skill care work occupations may redefine "women's work" as both men's and women's work" (p.355).

As Mackintosh (1997) rightly puts forward, “the contribution men have made to nursing history should be recognized more positively, thereby allowing male nurses the opportunity to fulfill their roles with full knowledge of their place in the historical background of the profession” (p.236). The present study also is in favor of bringing a change to the ‘feminization of nursing’ (O’Lynn, 2007) and thereby help men reinforce their caring identities. It also finds that caregiving becoming a gender-neutral activity as an after-effect of the enlarged representation of male caregivers is a possibility that cannot be ignored. Though the sample size of the study is limited, it is envisioned that the study would pave the way for future research and can be replicated in other parts of the country.

Ethical Approval

The study on home-based caregivers from Kerala was approved by the University of Hyderabad. The Institutional Ethics Committee’s certificate to conduct the research was granted on 09/03/2018 for the Application No. UH/IEC/2018/6.

Notes

¹ Role strain is “when an individual is likely to experience tension in coping with the requirements of incompatible roles” (Jary, D., & Jary, J., 1991, p. 538)

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