

**Care Giving to the Older Adults by the Older Adults: Exploring the Issues and  
Emerging Care Patterns within Families in Vadodara**



Mariyah Kapadia

April 2023

A Dissertation Submitted in Partial Fulfillment of Requirements for the Degree of Masters of  
Family and Community Sciences

M.Sc. (F.C.Sc.)

Department of Human Development and Family Studies

Faculty of Family and Community Sciences

The Maharaja Sayajirao University of Baroda,

Vadodara, Gujarat

## **CERTIFICATE**

This is to certify that the dissertation titled **Care Giving to the Older Adults by the Older Adults: Exploring the Issues and Emerging Care Patterns within Families in Vadodara** has been carried out independently by Ms. Mariyah Kapadia under the guidance of Ms. Bhavika Thakkar, in partial fulfillment for the degree of Masters in Child Development and Education for Sustainable Development from the Department of Human Development and Family Studies. This research is her original bonafide work carried out from April 2022 to May 2023.

**Prof. Uma**

**Ms. Bhavika Thakkar**

I/C Head

Research Guide, Assistant Professor

Department of Human Development  
and Family Studies

Department of Human Development  
and Family Studies

Faculty of Family and Community Sciences

Faculty of Family and Community Sciences

The Maharaja Sayajirao University  
of Baroda

The Maharaja Sayajirao University  
of Baroda

Vadodara, Gujarat

Vadodara, Gujarat



## **Acknowledgement**

The problems that I have faced during my dissertation have only made my learning process more enriching and fulfilling. But it would not have been possible without the constant support and guidance I have received throughout the year.

First and foremost, I would like to express my heartfelt gratitude to my esteemed research guide Ms. Bhavika Thakkar, for her immense support and guidance throughout my research journey. Her insights and nurturing support made this study, a joyful and learning experience. Her passion towards elderly became the base for my thesis. The discussions with her helped me understand different angles of the problem and it would always ignite my curiosity to know more. I would like to thank her to be patient while checking all my drafts and providing feedbacks that have helped me improve my writing.

I would like to forward my sincere gratitude towards the Department of Human Development and Family Studies for providing me this incredible opportunity to learn, grow and to achieve something, I thought I wasn't capable of. I would like to thank Prof. Shagufa Kapadia and Prof. Rachana Bhangaorkar for cultivating skills in me that have impacted my study and life deeply. I have always looked forward to the courses that Prof. Shagufa Kapadia taught us which included discussions and collective learning. I would like to thank all the teachers in the department for their help in various ways.

I would like to thank Dr Geeta Balakrishnan and Dr Mala Kapur Shankardass for taking out their precious time for validating my tool and giving me constructive feedbacks.

I am more than grateful to the participants of my study for participating and allowing me to understand their ideas and beliefs and making data collection the most fruitful experience of the entire journey. I would especially thank my roommates Akanksha and Fatema who were luckily my classmates too, for their constant support in helping me find participants for the

study and also for reviewing my ideas and providing me with their insights. The everyday discussions I had with them along with my other classmates have provided me a lot of clarity with my topic. Further, the time spent with them also acted as a buffer zone relieving me of the stress and helping me in becoming more stable with my thoughts and ideas.

Lastly, I would like to thank my family for their immensely valuable care and encouragement throughout the period. A special thanks to my partner Abdeali for his constant support, guidance, help and encouragement throughout this journey.

Above all I would like to thank the Almighty for every blessing and strength at every step.

## Table of Content

List of Tables.....	vii
List of Figures.....	viii
Abstract.....	1
Introduction.....	3
Review of Literature .....	5
Method .....	23
Results and Interpretation.....	28
Discussion and Conclusion.....	74
References .....	82
Appendix A: Consent Form.....	86
Appendix B: Tool .....	92
Appendix C: Kuppuswami's Scale.....	118

## **List of Tables**

Table 1: Age and Gender of the Participants.....	29
Table 2: Marital Status of the Participants.....	33
Table 3: Religious Distribution of the Participants.....	33
Table 4: Financial Independence Status of the Participants.....	36
Table 5: Gender wise Comparative Analysis.....	69
Table 6: Dyads living with and without Family wise Comparative Analysis.....	71

## List of Figures

Figure 1: Conceptual Framework.....	20
Figure 2: Theoretical Framework.....	21
Figure 3: Living Arrangements of the Participants.....	30
Figure 4: Living Arrangement of Children of Dyads Living by Themselves.....	32
Figure 5: Level of Education of the Participants.....	34
Figure 6: Self Perception about Health Among the Participants.....	35
Figure 7: Health Issues Reported By the Participants.....	36
Figure 8: Socio Economic Class of the Participants.....	38
Figure 9: Tasks by Caregiver for Care receivers.....	39
Figure 10: Typical Day Routine of Caregivers.....	40
Figure 11: Typical Day Routine of Care receivers.....	42
Figure 12: Paid Help/ Formal Caregiving.....	43
Figure 13: Availability of Support in the Absence of Main Caregiver.....	44
Figure 14: Areas where Help is Required or Given.....	45
Figure 15: Issues and Challenges of the Dyads Living by Themselves and with Family....	46
Figure 16: Positive and Negative Impact.....	49
Figure 17: Impact on the Relationship with Spouse Over the Years and now.....	51
Figure 18: Qualities a Caregiver Should Have.....	52



Figure 19: Advice for Older People by Caregivers and Care receivers.....	56
Figure 20: Satisfaction with Present Living Arrangements.....	57
Figure 21: Thoughts about Future of the Caregivers and Care receivers.....	59
Figure 22: Importance of Caregiving for Caregivers.....	60
Figure 23: Views on Care of Older People in Contemporary Society (Views of Both Caregivers and Care Receivers).....	61
Figure 24: Experiences of Caregivers and Care Receivers.....	64
Figure 25: Stereotyped Role Distribution.....	66
Figure 26: Views on Gender Roles at this Stage.....	67

### **Abstract**

Older couples living by themselves and caring for each other or older persons caring for their oldest old parents is becoming common in contemporary times. Longer life expectancy in the emerging socio-economic and cultural context has contributed to this shift where older adults are assuming role of care givers. The present study aims to understand aspects related to care giving in the families where older adults were the caregivers for their spouse, parents or relatives in their late adulthood. Qualitative study was conducted using exploratory research design and data was collected using semi structured interview schedule to get insights and understanding about lived experiences, roles, routines, challenges, emotions and impact on older care givers and receivers. The study also focused on knowing the different sources of support systems available to these families as well as their views on the care of older persons. The study results showed different kinds of living and care arrangements where old person took up care giving role in the capacity of a spouse, offspring or sibling. Spousal care was found to be one of the most common arrangements as older couples lived alone due to migration of children in other cities or abroad. Older spouses also provided care in multigenerational families where older persons contributed as carers for other older persons as well as other family members. More women were found to be taking up the care giving roles and gender differences were found in the way the care was conceptualized by caregivers. Older men took up the care giving roles in families comprising of older couples alone where other means of support were not available compared to couples living in multigenerational families. Physical and financial independence of the participants made independent living and caregiving easier and manageable for older persons. Domestic help, home based assistive care and professional care was used by the older care givers and care receivers. Formal care givers were used in times of medical emergencies and health issues. Although multigenerational families were found to be a preferred living arrangement, trend

towards older people opting for living alone for their own dignity, autonomy and personal space for self as well as adult offspring was found. Distant care emerged as a new care giving arrangement for families where adult caregivers were lived in other cities or countries. The study findings have pointed to some important insights to understand changing care giving patterns. It also offers valuable recommendations for interventions to facilitate the caregiving by the older adults in terms of availability of verified and trained formal carers as well as community based living arrangements for older persons living alone.

*Keywords:* Older people, Caregiving, Caregivers, Formal care, Distant care.

## **Introduction**

The population of older people, those who are above 60 years of age, is fast growing due to increase in life expectancy. Better health care, hygiene, healthier lifestyles, sufficient food and improved medical care mean that one can now expect to live much longer than before. Because of urbanization, migration, changes in social values and low fertility rates, the number of family members available to care for the elderly has decreased. Women entering the workforce have also changed the way older persons are cared for. In Western nations, it has been a norm for children to live independently as they attain adulthood and live an independent life. Older parents tend to live alone and avail a range of formal caregiving services as they become more dependent. In contrast to this in India, children especially sons and daughters in law are traditionally expected to look after their aging parents.

India is experiencing rapid changes in various spheres including the social, economic and cultural realities. Due to globalization of education and economic opportunities, geographic boundaries have become more fluid. It is not uncommon to see young adults moving and settling to bigger cities and migrating to developed countries for better educational and employment opportunities and better life style. Parents in fact actively help children in this move. Vadodara city is an example of increasing trend of young population migrating to countries like UK, Canada and Australia for education and gradually settling there in long term. Increased number of agencies that help students to go abroad, the international education fairs and trends among university students are evidences of this trend. All these changes are paving ways for new types of families comprising of older parents living alone in India.

Simultaneously there are changes in terms of preference of increased autonomy and personal space across generations leading to nuclear and micro nuclear families even when the children are living in the same city. They may prefer to live closeby and support each other in times of need at the same time enjoy personal space in daily lives, thus enjoying the best of the both worlds. Like in other parts of India, Vadodara too is now host to retirement living apartments and community living experiences for older couples and individuals to support independent living.

In view of these factors we see various types of families and living arrangements especially for older persons. Due to increased longevity it is also not very uncommon to see the older couples living alone and caring for each other rather than by their offspring. There are also the oldest old parents who are cared for by their offspring's who are approaching or well into their late adulthood. These newer forms of family living arrangements, their experiences, support networks, issues and challenges are emerging as the areas of research as little is known about them.

There is a dearth of data on the proposed topic in specific as the changes are fast emerging. The study aims to understand the living arrangement, care giving experiences and challenges of the older care receivers as well as care givers. Understanding of the changes, challenges, strategies adopted by these families and the emerging need for services will be instrumental in providing recommendations for services and policy making to come up with sustainable solutions for care giving to the older adults by the older adults.

## **Review of Literature**

Late adulthood is emerging as an important area of research due to major shifts at micro and macro levels including rapid demographic changes, socio- cultural transitions, and medical and technological advancements. There are various reasons why research in gerontology with a focus on care giving is becoming increasingly important.

### **Demographic Changes and Projections**

Due to their vast population, India, and China are the two largest nations having a sizable part of the world's elderly (Panigrahi & Syamala, 2012). Demographic changes, globally as well as in India, such as changes in fertility and mortality rates and higher life expectancy are major causes of population ageing. These changes are also greatly supported by revolutions and advancements in medical field, availability and accessibility of better health care facilities and improved life styles (Ingle & Nath, 2008).

The age structure of the global population is drastically changing, with fast population aging being one of its most noteworthy features (Bloom, 2011). There are approximately 760 million persons over the age of 60 in the globe which is 11% of the total population. According to the global estimates, 22% of the world's population, or 2.0 billion individuals, is projected to be 60 years of age or older by 2050. Furthermore, it is anticipated that between now and 2050, the percentage of people in the globe who are 80 or older will be more than quadruple, going from 1.5% to almost 4%. In comparison to the 3.7-fold rise in the world's population that is anticipated to occur between 1950 and 2050, this translates to a 10-fold increase in the population of people 60 and older and a 27-fold increase in that of those 80 and older (Arokiasamy, 2011).

Women have had fewer children than in the past, with the exception of the post-World War II baby boom. According to Cahallan et al. (1980), the average family size, which was 3.4 in 1975, will continue to decline and reach 3.1 in 1990. As a result, there will be a smaller total pool of children who can assist elderly parents and a lower likelihood that they will be female. The growth in the percentage of women in the labor market is the second trend. Currently, 51% of all women between the ages of 18 and 65 who are working are employed. 60% of women between the ages of 45 and 54 who are most likely to have caring obligations are employed (Brody, 1981). Despite recent research showing that working women do not forget their caregiving duties (Brody, 1981; Cantor, 1980; Horowitz, 1982; Noelker & Poulshock, 1982; Sherman et al., 1982), their employment status may require different caregiving patterns in the future as well as more shared responsibility among male and female siblings (Horowitz, 1985).

India's age structure is being influenced by the same factors, including a rise in life expectancy and a decline in fertility in line with global trends. An Indian born in 1950 might anticipate living for 37 years, however now that number is close to 70 years, and by 2050 it is expected to grow to 74 years. From about 6 children per woman in 1950 to only 2.6 children per woman in 2010, India's fertility rates have dramatically decreased. (Arokiasamy, 2011; Bloom et al, 2010; Pal, 2007)

India is now experiencing demographic changes and in future decades, India's population is expected to age dramatically, yet there is a dearth of thorough study and effective strategy to address this shift. According to forecasts made by the United Nations Population Division, the percentage of Indians aged 60 and older is predicted to rise from 8% now to 19% by 2050 which would be approximately 323 million people that is more than the whole US population in 2011. Arokiasamy (2011) predicted several challenges because of this demographic change and further envisaged that there will be a greater emphasis on

India's traditional reliance on family networks to provide older people with care, companionship, and financial support. Focus thus has to be on changing household dynamics and patterns of spatial mobility among younger family members. Policy makers and researchers worry about the effects of increase in the number and proportion of older people especially in the context of shrinking care giving networks. This is because growing old is linked to functional impairments including loss of movement, vision, and hearing, as well as an increase in disability and loss of independence. Sustaining health and quality of life in an aging population is perceived as a biggest challenges facing society today (Khaw, 1997).

### **Socio-Cultural Changes**

Like any other type of care, elder care in India has historically been organized through the joint family structure. Within a single family, several generations shared resources and income. Men often handled social and financial issues, while women handled domestic duties and other basic duties (Bhat & Dhruvarajan 2001; Prakash 1999; Brijnath, 2012).

The traditional extended family structure in India however has also been disintegrating; at the moment, older people in India are mostly cared for privately, but these family networks are under pressure from a number of sources (Arokiasamy, 2011; Bloom et al, 2010; Pal, 2007).

Family relations and by its extension, methods of elder care have evolved as a result of migration, urbanization, consumerism, and changes in the role of women in modern Indian culture (Patel & Prince, 2001; Varghese et al, 2004). Migration, whether domestic or international have increased the number of nuclear family units, leaving elder family members behind to care for themselves. The pattern is so widespread in some areas of India that acronym for it has emerged: PICA, or Parents in India, Children Abroad (Prince et al 2007). The responsibilities of women have also evolved, and because many of them are now



employed full-time, they are less available to provide care to the elderly. In circumstances when children are not living with their elderly parents but are attempting to retain strong links and making attempts to provide care and support, even if they are separated by great distances, distance care is one such newer method of caring that has recently arisen (Kaushik, 2020).

Denser urban living, greater living expenses, and more consumerism are all contributing factors that make many families less likely to support the social, economic and psychological requirements of their older parents (Patel & Prince, 2001). Therefore, many academics argue that elderly adults are not as respected or as solidly positioned in their family's hierarchy as previous generations were (Dharmalingam 1994; Jamuna2003; Kumar 1996; Mahajan 2006; Brijnath, 2012).

### **Changes in Living Arrangements and Care Giving Across the Globe**

According to a series of studies conducted in the 1980s, the vast majority of elderly people in the four Asian nations (Taiwan, Thailand, Philippines and Singapore) that make up the Comparative Study of Elderly in Asia project live with one or more children in intergenerational households. Asis, et al, (1995) summarised and pointed at some of the important trends in Asian countries which suggest that

- High rates of co-residence suggest that a common home environment and family care for the elderly are still the norm in this region of the world, as seen by the high rates of co-residence, has occurred like in Taiwan and Singapore. The family still serves as the primary caretaker for the elderly not withstanding economic achievement (Asis, et al, 1995).
- Family was seen as the ideal environment for providing elder care and some family members were expected to help the elderly more than others.

- The spouse, typically the wives were senior partner's initial carer. Children were often the next in line as the likely caregivers if the spouse is not accessible, as in the case of elderly people who are widowed.

Velkoff (2001) presented similar findings based on a cross-national analysis of elderly people's living arrangements. First, older men are far more likely to live in family settings, often with a spouse, whereas women in industrialized nations are much more likely to live alone. Second, there has been a rise in the percentage of older people in affluent nations who live alone. Thirdly, adult children are a common living arrangement for elderly men and women in emerging nations. Fourthly, although it varies much globally, the usage of non-family institutions for the care of the aged and weak is generally minimal (Velkoff, 2001).

This suggests that similar to India, in other Asian countries families remain to be the most preferred source of care giving for the older persons. However, when family members live apart, each generation becomes more responsible for taking care of their own daily requirements, and a sizable proportion of older people who are unable to take care of their own needs may have to rely on formal care or institutional care.

Late adulthood is further divided into three groups and the age group of the older persons is an important factor that determines the care experiences of the older persons within familial or alternate care context. This is because their circumstances, characteristics and needs are likely to be very different. The younger-old are often in a better position to make decisions since they are more economically engaged and generally in better health. The older old may have very few options, especially those related to their living circumstances, due to declining health and economic inactivity (Asis et al, 1995).

## Meaning and Types of Care

Care giving for older persons can happen at various levels by various people. It can range from informal care by family and friends to formal care by charity based or commercial entities. Formal care also spreads out over a continuum, with domiciliary support services—services that help older people live in their own homes at one end and residential care in various types of institutions at the other. There are several middle-ground types of service that fall between these two extremes (Djellal & Gallouj 2006).

According to Djellal & Gallouj (2006) care is provided informally (by family members, typically women: wives, daughters, and daughters-in-law) and formally through the "market" and/or networks by hiring professionals to provide market services, whether they be employees of a firm, a non-profit organization, or the elderly people themselves. The increasing trend is towards care where formal and informal ways of supply are frequently blended.

As noted by Byrne et al. (2009), multiple informal care providing is still understudied. First, informal caregiving by friends and family members is numerically significant (Kalwij et al, 2014). According to Spillman and Pezzin (2000), 13.1% of senior citizens in the United States who have a chronic handicap get care from friends or family members other than their spouses or children. On average, acquaintances, neighbors, or relatives who are not children provide 30% of the weekly hours of informal care provided to elderly people (aged 65 or older) in nine different European nations (Kalwij et al, 2014).

According to van Houtven and Norton (2008), elderly people have stronger financial and blood ties to their children than to friends and other family members, but a retired friend or neighbour might find it more enjoyable to spend time helping than would a daughter who is working age and may also have children of her own to look after (Kalwij et al, 2014). Third, Lakdawalla and Philipson (2002) demonstrate that the requirement for formal care has

diminished as a consequence of declining male mortality over time, which translated into wives experiencing widowhood for a shorter time and caring for their spouses for a longer duration (Kalwij et al, 2014).

Kaplan & Berkman (2021) have summarised some important findings in regard to the family care of older persons which suggest that Family members' ability to provide care relies on their financial circumstances, their family's structure, the depth of their ties, and other demands on their time and energy. Family caregiver responsibilities can vary from uncomplicated part-time care to complex full-time care. He also pointed that even though society tends to view family members as having a responsibility to care for one another, the degree of familial and marital duties vary among societies, families, and particular family members.

Supportive services and additional services may improve the desire of family members to provide care including counselling, help learning new skills, and family mental health services (eg, personal care [assistance with grooming, feeding, and dressing], home health care, adult day care, meals programs). More amenities might be provided on a daily basis or as temporary or permanent care for caregivers. Some senior citizens who require substantial care do not have family or acquaintances that are willing, able, or accessible to help, and as a result, their needs go unfulfilled and they may experience social loneliness (Kaplan & Berkman, 2021).

There are many factors in favour of informal care. Houtven and Norton (2008) have investigated whether or if informal care is a replacement for or addition to formal care and found that informal care may be preferable and can lower medical costs. Informal care might take the place of conventional home and nursing facility care. This impact was discovered by Bolin et al. for formal home care as well. Even though official, paid, and institutionalized caregiving is on the rise, informal caregiving by close relatives most often a partner, kid, or

grandchild remains the most prevalent type of caregiving (Herrmann et al., 2010).

Additionally, many elderly people decide to remain in their present home for as long as it is practical rather than move into a care center (Cho, J. et.al. 2018).

The enormous rise in Europe's elderly population has sparked a quest for innovative methods to deal with the pressures brought on by demographic change. The term "ageing in place" is one of the new policy approaches that appears as the mainstream recommendation for housing and care measures that strive to preserve and prolong as long as possible the autonomy that allows older people to remain in their own home as a substitute for institutionalization (Davey et al, 2004; Fernández, 2016).

The claim that older people prefer to remain in their own homes is frequently used to support the implementation of ageing-in-place policies (Jong et al. n.d). Additionally, the overall decline in the number of multigenerational homes in Europe, which today ranges from less than 4% in Sweden, Denmark, and the Netherlands to between 17 and 24% in Italy, Spain, and Greece (Ogg & Renaut 2006) has also given credence to the idea that elderly people, for the most part, want to live in their own homes (Fernández, 2016).

It is a known fact that unlike western countries, in India more for cultural and traditional reasons than for economic factor, informal family care has been the most prevalent kind of caregiving (Panigrahi & Syamala, 2012). However, similar to many other traditional communities today, India confronts a special challenge when it comes to caring for the old. The family, friends, and other support systems for the elderly are increasingly vanishing, and they are ill-prepared to deal with illness and incapacity on their own. The idea of alternate arrangements for the care of the elderly through institutional support has emerged as a result of this occurrence.

According to recent statistics, India has more than 1,000 old age homes, the most of which are found in the south. There are two forms of senior housing: free and paid. The "free" kind takes care of the elderly who are in need but have no family to care for them. They receive housing, nourishment, clothes, and medical attention. Services in the paid kind can be purchased for a fee. Numerous researches have covered a range of factors that contribute to older people residing in nursing facilities. Children moving in have been highlighted as a key factor in older people moving into nursing facilities. Even though old age homes first began operating in the latter part of the 19th century, India's growth and development of these facilities is still insufficient (Panigrahi & Syamala, 2012).

There are thus interesting shifts in caregiving where European countries are trying to establish merits of informal care whereas India is struggling to maintain the traditional system of family based informal care. The latest policy level initiative recognises the importance of ageing in place however also attempts to strike a balance by being aware of changing socio-economic changes. Thus, it also focuses on Government support for creating better institutional facilities as well to address needs.

## **Cultural understanding of Care**

### ***Filial Piety and SEVA***

There are different cultural notions that define importance and motivation of care for older persons. As part of the conventional understanding of Confucianism, Filial Piety (FP), a major motif in Asian culture, is understood as concern for one's parents. Older adults could have high standards for FP in their offspring. How much one feels their expectations have been met may have an impact on how they feel about the experience of growing older (Laidlaw, 2010). It is widely believed that Asian civilizations value respect for elders more than Western society (Sung, 2000). As a component of Confucianism, which upholds the

family as the primary social unit in Asian civilizations, the idea of Filial Piety (FP) continues to have significant cultural influence (Park & Chesla, 2007; Laidlaw, et al, 2010).

In Asian civilizations, FP plays a significant part in defining and determining intergenerational connections. FP can be described in terms of the positive and bad effects it has on both the person and society. While FP may promote intergenerational harmony and foster familial togetherness, it may also foster rigidity and authoritarian parenting practices. (Kuang-Hei, 2003; Laidlaw, 2010). More frequently, FP alludes to a collection of actions and attitudes that show respect for, love for, and concern for one's parents. Even though FP is sometimes reduced to parental care and obedience, it is actually a multifaceted notion among Chinese people and has historical roots to Confucianism, giving the traditional foundation for the concepts of respect for elders (Sung, 2001). Therefore, it's possible that older individuals have high expectations for FP from their adult children (Laidlaw, 2010).

Based on intergenerational reciprocity and the significance of doing Seva, older people had a societal expectation of care from their offspring (Lamb, 2000, Vatuk & Lynch, 1990). Seva, which means "service," is a multifaceted idea that includes the mental, emotional, and physical support provided to older family members by their younger relatives. Respect is at the core of the idea and such tenderness is viewed as a type of devotion of the divine (Brijnath 2012).

### ***Experiences and Impact of Care Giving on Care Givers***

Although there are cultural, traditional and economic reasons for family based care of older persons, it must also be kept in mind that care of older persons, especially with increased dependency and high health needs tends to affect care givers. Especially when we are talking about care givers who are also in their late adulthood, calls for understanding these dynamics better. Families (spouses, children, and children-in-law) frequently provide

casual care for their elderly parents as an option. However, caring for family members has been connected to chronic worry and increased caregiver load, which may lead to health issues (Family Caregiver Alliance, 2012; National Academies of Sciences, Engineering, and Medicine, 2016).

Numerous risk factors for caretaker burden have been found by earlier researchers, including caregiver demographics, care receivers' personalities, and functional state. For instance, the quantity of caretaker burden was more likely to increase as the care-recipients' physical or cognitive function declined (Pinquart & Sorensen, 2007). In addition to being related to caretaker burden, the personality of care recipients has been shown to affect relationships with their caregivers (e.g., agreeableness, openness) (Lockenhoff et al, 2011; Robins et al , 2000). Regarding caretaker traits, age, connection to the care receiver (spouse or children), and co-residence were also important predictors of caregiver health (Pinquart & Sorensen, 2007).

One aspect of how caregivers evaluate the behavioural and cognitive effects of caring is caregiver burden. In the research on caring, women frequently report higher levels of emotional suffering throughout the course of their lives (Horowitz, 1985; Schultz et al, 1990). Less conclusive results have been found on gender differences in caregiver burden, although most research support the notion that female carers experience greater levels of burden than male caregivers (Horowitz, 1985; Pruchno & Resch, 1989). Studies on impact of caregiving on care givers have emphasized on physical exhaustion, sleep deprivation, and fatigue (Greenwood, 2019). In Greenwood's (2019) study, Caregivers frequently expressed unfavourable changes in their lives after becoming caregivers, either overtly or implicitly. Many of these changes are included within the topic of loss. Losses in freedom and leisure activities, fewer options, and financial losses are all included. The same study also found that



despite having a generally optimistic view, the caregivers frequently spoke of feeling guilty. This frequently happened if they left the care recipient alone to have fun or if they were upset with them.

Greenwood (2019) also emphasised that Future worries were a prevalent aspect one for many caregivers. Many were concerned that they wouldn't be able to continue providing care in the event of illness or death, particularly if they were providing care for someone who was substantially younger than themselves, such an adult child. This seemed to affect the oldest caregivers the most. Participants in this study believed older caregivers were even less likely to ask for assistance than younger caregivers. Caregivers of all ages usually do not seek support for their roles. A variety of theories were put out, including the idea that older individuals are more inclined to "soldier on" and are less likely to ask for assistance because they have a higher sense of duty or pride.

In Greenwood's (2019) study, caregivers frequently emphasized the good aspects of caregiving rather than just talking about the difficulties. The benefits and satisfactions of caring and good elements of caring were explored. Caregivers talked about developing new skills and self discovery in the process of caregiving. Due to these positive elements, despite the difficulties, caregivers seemed to be able to go on providing care coupled with their optimism and affection for the care receiver.

### **Gender Differences in Caregiving**

Studies have tried to understand the gender differences in caregiving by understanding gender disparity and impact of caregiving. Women often have greater adverse subjective reactions to providing care than do males. According to Zarit (1982), women have more burdens and psychological anguish as a result of providing care, along with decreased morale (Gilhooly, 1984). According to Fitting et al. (1984), women report greater symptoms and negative sentiments and have higher depression scores (Siegler & George 1983). Women

are more prone to anticipate institutionalizing the patient and experience higher remorse for not being able to offer complete care, according to Zarit (1982). For women more than for males, emotional stress may be a stronger predictor of the inclination to institutionalize. According to Morycz (1985), physical labour for males and strain for women were significant predictors of the desire for placement (Barusch & Spaid, 1989).

Given that these duties are extensions of the nurturing activities/behaviors undertaken as mothers and spouses, the gender role socialization theory predicts that female caregivers will be more likely than male caregivers to perform personal care and domestic responsibilities., possibly because they rely more exclusively on the primary caregiver; male caregivers receive more support from informal and formal sources to ease the burden of care; and men cope more effectively with life stresses in general (Billings & Moos, 1981) and with caregiving in particular (Fitting & Rabins, 1985). Studies suggest that male caregivers are found to be better suited for tasks like money management that have a set completion date and can be completed at the caregiver's discretion. Furthermore, female caregivers may be taught to respond to equivalent degrees of need more than males do due to gendered norms of acceptable actions by caregivers and frail older people (Miller & Cafasso, 1992).

Researches on kinship networks in old age have shown a bias in favour of female linked networks. Every aspect of parent-child interactions may be said to have this quality. Compared to males, women often reside closer to their families of origin and spend more time with their extended relatives. When it becomes impossible for them to live alone, elder women are more likely than older males to move in with their children, and these children are often daughters rather than sons (Troll et al., 1979). According to certain research, girls are seen as being emotionally closer to their parents than males are (Adams, 1968; Jackson, 1971; Johnson & Bursk, 1977).

Daughters traditionally assumed caregiving responsibilities, they have a stronger emotional attachment to their family, and they have more flexible free time in their role as homemakers than do their male counterparts in their occupational roles, according to the usual explanations (Horowitz, 1985).

### **Support for Caregivers**

Some studies have talked about needs and importance of support for caregivers as it may consequently be advantageous to them. The need for assistance may be even larger for elder caregivers since they frequently provide more intensive and personal care, put in longer shifts, and are frequently co-residents (Miller & Cafasso, 1992).

Effective support for caretakers includes emotional support, counseling, respite care, and physical assistance with caregiving duties. Doctors, nurses, social workers, or case managers can frequently provide solace to caregivers as well as instruct them in caregiving methods or helpful information (Kaplan & Berkman, 2021). Kalpan and Berkman (2021) also outline the steps that caregivers should also take to prepare for caring and avoid burnout

- Attending to their own material, spiritual, mental, recreational, and bodily requirements.
- Asking for support from neighbors and other family members when required for caring.
- Researching additional non-profits that offer emotional support and caregiving help (such as counselling, home health care, senior day care, feeding programs, and respite care).  
(such as support groups)

Questions related to caregiving for older persons in India are still in emerging phase however the pace at which society is changing requires in depth and all encompassing researches to understand the issues related to caregiving and caregivers. More older persons

assuming caregiving responsibilities would also mean need for better supportive facilities for older caregivers.

## Conceptual Framework

**Figure 1**

### *Conceptual Framework*

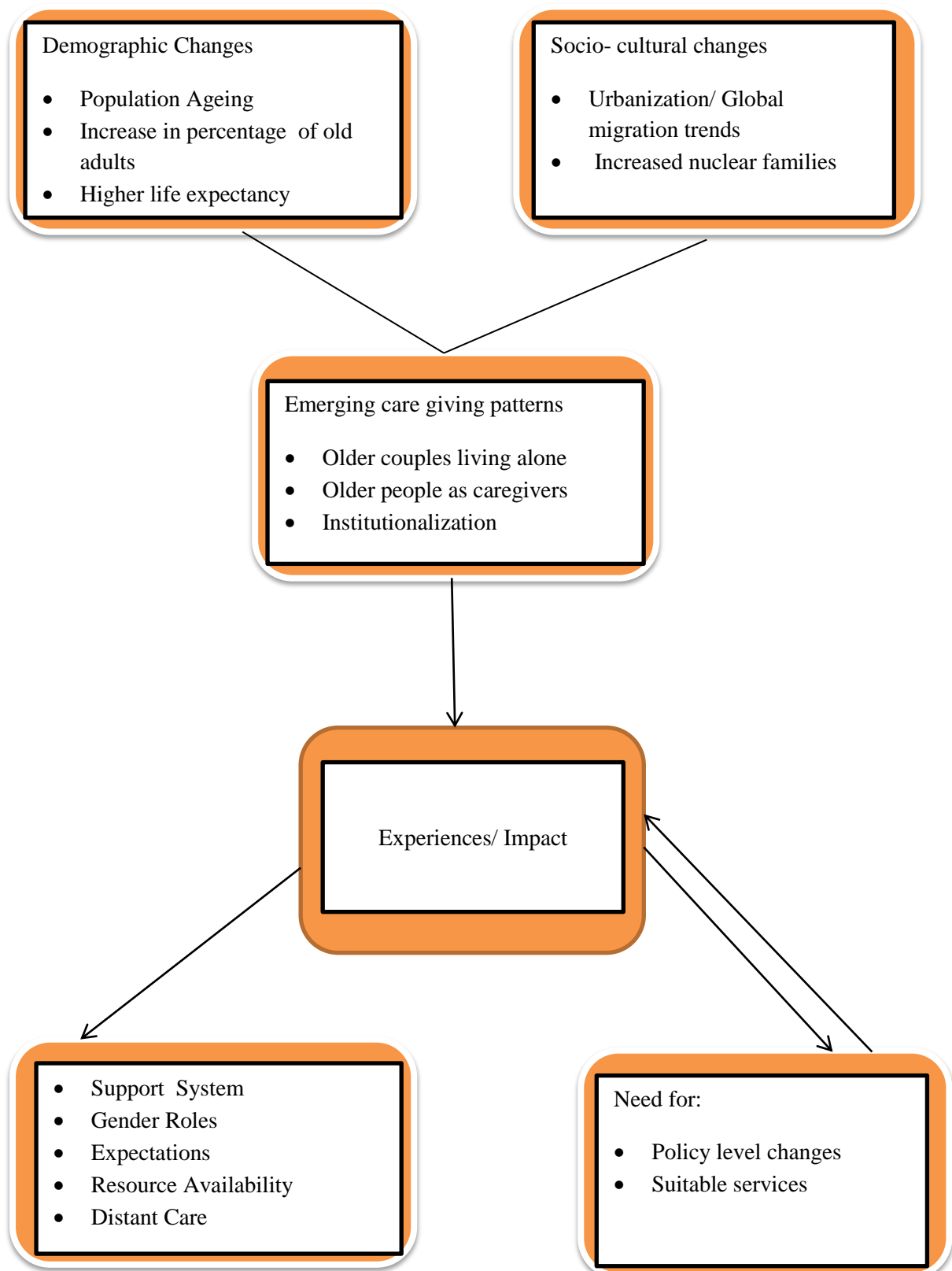
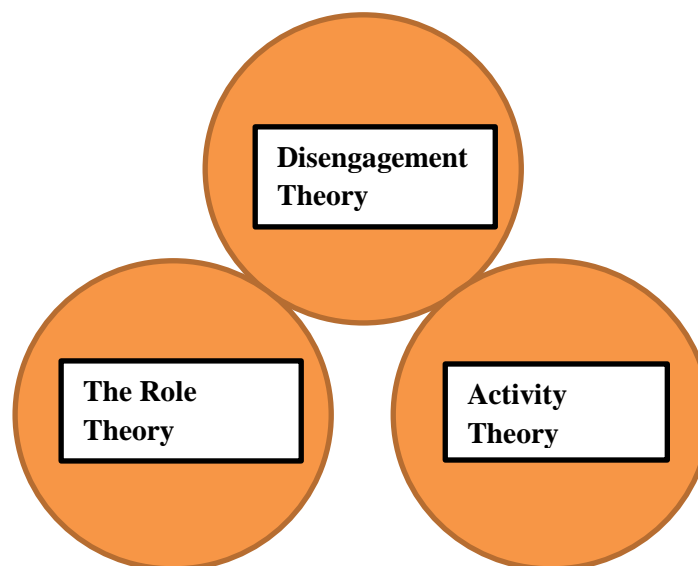


Figure 1 displays the conceptual framework where in shows that the study talks about the demographic changes like population ageing and increase in life expectancy due to better medical facilities and technology. The framework then talks about the socio cultural changes about how there is increase in number of nuclear families due to urbanization and migration. These 2 factors have led to the emerging care giving patterns of the elderly, where in there are older couple who are living alone, some of them are the primary caregivers and lastly the emergence of Institutionalization. The study then explore the experiences and the impact of both the caregivers and care receivers in terms of the support system, gender roles, distant care, expectations and resource availability. The study recognizes the necessity for numerous policy modifications and appropriate assistance for the elderly owing to their diverse experiences and impacts. If older persons could access specific services, their experiences and impacts could change.

## Theoretical Framework

**Figure 2**

*Theoretical Framework*



- Through the Disengagement theory by Elaine Cumming and William E Henry, proposed that older people want to withdraw themselves from all the social roles and interactions, due to various reasons like, realizing that death is imminent; reputation might get

damaged due to the loss of skills, feeling incapable of doing things. In the given socio-cultural realities though, disengagement may not be possible as older adults may be expected to take on the roles and responsibilities of self-care and care of others.

- On the other hand through the Activity Theory Robert Havinghurst suggest that older people who engage in daily activities that they perceive as productive tend to age successfully. The changed context of caregiving makes active engagement in caregiving crucial and thus may increase the likelihood of wellbeing.
- Role theory links the successful adaptation to old age with adaptation to changing roles as the roles may significantly change due to role losses and introduction of new roles. The present study will attempt to understand how older persons are coping with extended caregiving roles and its impact on them
- The study will attempt to comprehend the changing roles of the elderly, how some roles change, and how some cease, through the Role Theory by George Herbert Mead and Ralph Linton in sociology and social psychology, respectively. How do they handle switching between roles, and does it help or hinder them?

## **Rationale**

There is a dearth of data on emerging trends in living arrangements and care of older persons in the light of increasing nuclear families, migration of young family members and increasing number of families comprising of older persons living by themselves. The given study will help in understanding the lived experiences, support system and challenges of the older care receivers and caregivers, whether and how it impacts the lives of older caregivers which will help to understand life in late adulthood in contemporary urban context.

Understanding of the effective strategies adopted by as well as based on the expressed needs of the older persons will help in providing recommendations for services and policy making to come up with sustainable solutions for this sort of care giving.

## **Method**

This chapter provides an overview of the study methodology, data collection procedures, and analysis procedures. It consists of the following components: research objectives, study design, sample, sampling procedure, research tools, data gathering and analysis procedure, and ethical issues.

### **Objectives**

#### ***Broad Objective***

To explore and understand the patterns, experiences and issues of caregiving in families, where caregivers and care receivers both are in their late adulthood.

#### ***Specific Objectives***

- To explore the different living arrangements where older person is the care provider to another older person.
- To understand the impact of the caregiving on caregivers.
- To understand the issues and challenges related to caregiving by the older adults.
- To gain an insight into the experiences and views of older persons about care of older persons in present context as caregivers and receivers.
- To discern the differences in roles and experiences across gender and living arrangements.



## **Research Design**

Qualitative and Exploratory research design - The study aimed to understand aspects related to care giving in the families where primary care givers for the older adults were themselves into late adulthood. The qualitative approach was used to get insights and understanding about their lived experiences, roles, routines, challenges, emotions and impact of care giving. The study also focused on knowing the different sources of support systems available to these families.

## **Sample**

***Sample Size:*** 25 Dyads (Caregivers+ Care receivers)

### ***Sample Selection Criteria***

The dyads of care givers and care receivers who are both 60 years and above including

- Older couples living alone
- Older couples living in multi-generational families
- Parent –Offspring in multi-generational families
- Any other dyads of older caregiver and receiver in informal context

### ***Sampling Technique***

The technique used for collecting sample was purposive snowballing technique wherein the research participants suggested and referred the researcher to the other potential participants.

## **Tool**

Data were gathered using a semi structured interview schedule and covered following components:

- **Background Information**

This section includes, Age and Gender, Living Arrangements, Living arrangement of Children of Dyads living by themselves, Marital status, Religious Distribution, Level of education, Self -perception about health, Health issues, Source of income and Socio Economic class of the participants.

- **Practical aspects/issues in care giving**

This section includes, Issues and Challenges of the Dyads living by themselves and with family.

- **Impact on the care givers**

This section includes the positive and negative impact of caregiving on caregivers and also the impact on the relationship with care receiver over the years and now.

- **Support systems available and used by these families**

This section includes the different support available to the main caregiver in the absence of them.

- **Strategies and solutions used by the carer**

This section includes the different ways the caregiver takes care of their own self and different strategies used by them in order to cope up with challenges.

- **Existing and expected care arrangements**

This section includes the preferences for different arrangements and how much the participants are satisfied with their current lifestyle.

### **Content Validation**

The tool was shared with two experts in the field who, Dr Geeta Balakrishnan, a senior Social Work Educator, Practitioner and Researcher and Dr Mala Kapur Shankardass, a sociologist, Gerontologist and Health Social Scientist. Experts reviewed the tool and shared their feedback. The suggested changes were incorporated before the tool was content validated.

### **Pilot Testing**

Pilot testing of the tool was conducted with an older couple living on their own, wife 75 years of age (care giver) and husband 85 years (care receiver). The interview lasted around one hour, in total. Interview was conducted separately for both the care giver and receiver to ensure that the participants could freely express their views.

The pilot study was conducted in order to:

- Check whether the tool made by the researcher was relevant and suitable to collect the information it intended to collect.
- Check whether the tool was understandable for the respondents
- Check whether the language of the tool was appropriate.

### **Procedure of Data Collection**

25 dyads of care givers and care receivers were interviewed by the researcher. The caregivers and receivers, both were 60 years and above. Due to the qualitative nature of the study, on an average the interview took about an hour for both the interviews. The interviews

were held in person in the households of the respondents. The interviews were audio recorded with the consent of the participants in order to avoid loss of any important information.

### **Data Analysis**

After interviewing the participants, the recorded interviews were transcribed. Following that, the responses were translated into English. Responses under different broad areas and components were categorised and coded to identify different emerging themes. The codes were then merged to identify the broad themes. The results were then discussed under these themes and explained with the supported of the verbatim responses.

### **Ethical Considerations**

- Participants were informed in detail about the aims and objectives of the study.
- Informed consent was sought from the participants for their participation in the study.
- Interviews were audio recorded with the consent of the participants.
- Confidentiality and anonymity was assured and data was strictly used for the research purpose only.
- The participants were also allowed to withdraw from the study at any time if they wished to.
- Researcher reflexivity was consciously used to handle the questions with sensitivity and avoid researcher's bias. Ethical reflexivity was used to avoid any negative impact on the emotional wellbeing or violation of participants' rights.

## **Results and Interpretation**

This chapter presents the results and interpretation of the study which is divided into the following sections:

Section 1- Background Information of the Participants

Section 2- Living and Caregiving Arrangements

Section 3 - Issues and Challenges of the Dyads living by themselves and with family.

Section 4 - Impact of Caregiving on Caregivers

Section 5 - Views and Experiences of the older caregivers and receivers related to caregiving

## Section 1

### Background Information of the Participants

This section includes background information of the respondents and includes their basic socio-demographic information as well as self-perception of health.

**Table 1**

*Age and Gender Distribution of the Participants*

Age Categories	Caregivers (n=25)		Care receivers (n=25)	
	Men (n=7)	Women (n=18)	Men (n=15)	Women (n=10)
Young old (60-74)	4	16	11	5
Old old (75-84)	2	1	3	4
Oldest old (85-99)	1	1	1	1

Table 1 explains the age and sex distribution of participants. Majority of the participants were in young old category of late adulthood stage. Majority of the participants who identified themselves as caregivers were women (18 participants) whereas majority of the care recipients were men (15 participants). Result showed that more women engaged in care giving compared to men. Although fewer in number, it was noteworthy that 5 participants (3 men and 2 women) continued to play the role of the care giver at the advanced age of over 75 and even 85 years of age.

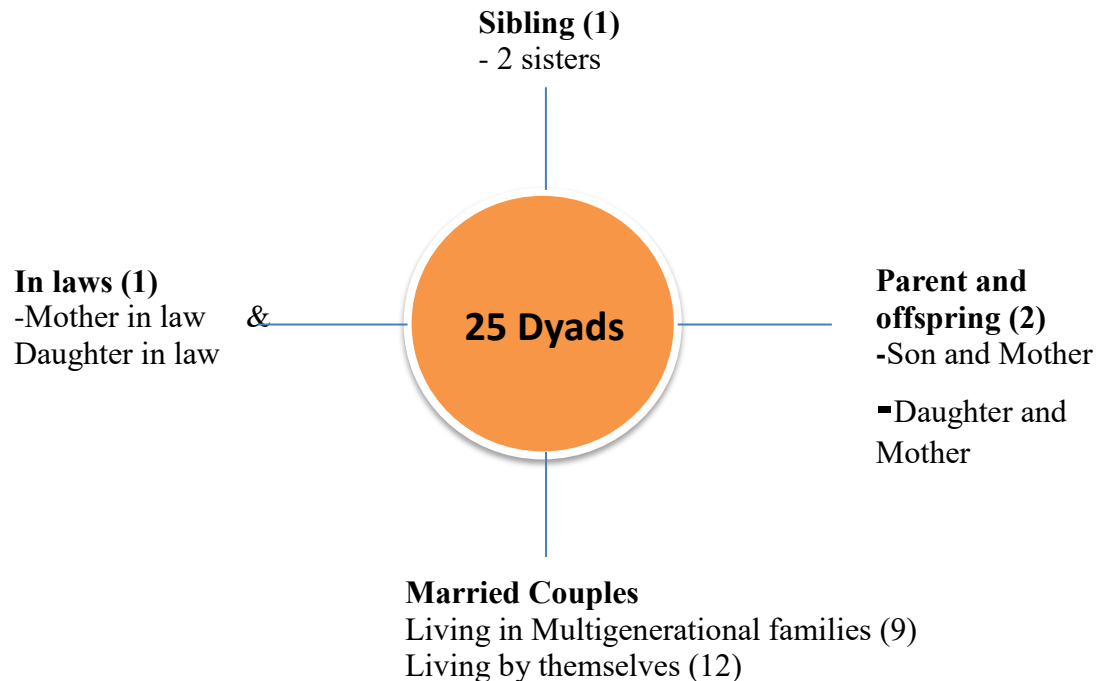
**Figure 3***Living and Care Arrangements of the Participants*

Figure 3 depicts the relationships of caregiver - care receiver dyads. Majority of the dyads were married couples (21) where the spouse assumed the role of the primary care giver. Twelve dyads out of these lived by themselves as a household consisting of only themselves. Nine dyads on the other hand lived in multigenerational families consisting of their son(s) daughters in law and grandkids. 3 dyads were intergenerational dyads where caregiver were either a married son, married daughter or widowed daughter in law. Only one dyad comprised of two sisters wherein the younger sister was a caregiver to her elder sister.

There were only two care recipients who required support and physical assistance with Activities of Daily Living, making it clearer to define their roles as caregiver or care receiver. In multigenerational families, dyads such as son and mother, daughter and mother or daughter in law and mother in law, the roles were clearly defined with younger generation

assuming the role of a caregiver due to various reasons such as role expectations, better health and capacities, sense of duty, love and care.

Among all the other dyads, the role of caregivers and recipients were dynamic and changed as per the need such as an episode of ill health or certain physical limitations or instances of hospitalization. Although many participants stated that they were mutually caring for one another roles, during the interview, while answering some of the questions, there was more clarity on who the primary care giver and care receiver was. It was found that the roles were defined more on traditional gender based understanding of the tasks. For example men assumed role of caregiver by providing for financial needs, advice, taking certain important decisions, doing the outside tasks such as shopping and medical appointments. Other than these specific tasks, most times women were identified as caregivers, by men and women both. Cooking, meal planning, administering medicines, providing physical support and assistance and taking lead in social obligations were some of the tasks generally performed by women.

Women were usually expected to be the care provider for their husbands. As this verbatim from a 76 years old man who expressed ***“have bairao to dhyaan rakhej ne ghar ane parivaar nu, kartavya che ehmnu”*** ( *women will take care of our homes and families, it is their duty*) . Another similar response from a 72 years old woman was ,***“bairao ni jaat che hame, apni faraj and javabdaari che”***(*which means, we are women, it is our duty and responsibility*).

There were a few exceptions (n=7), where men performed the role of caregivers and looked after their wives because the wife had some health difficulties that made taking responsibility for the household difficult.



This result indicates presence of strong gender role expectations in most men as well as women. In majority of the dyads, even when there was no physical dependency or assistance needed, women were identified as caregivers. Men identified as caregivers when women were unable to perform certain household and caring tasks due to health issues.

**Figure 4**

*Living Arrangement of Children of Dyads Living by Themselves*

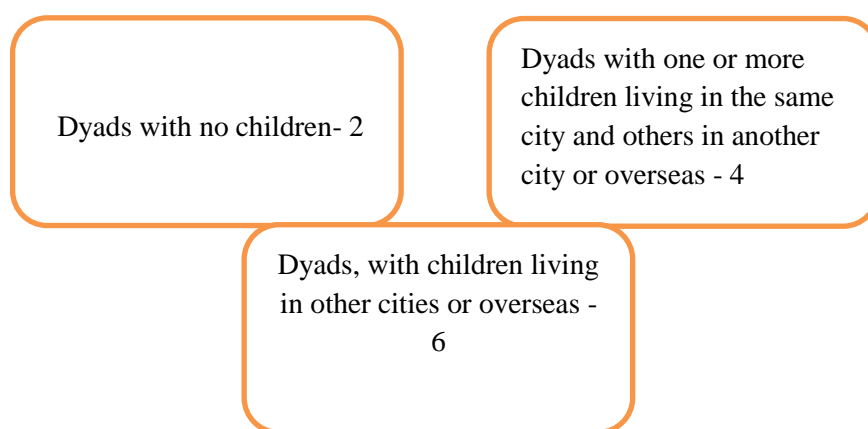


Figure 4 shows that in all there were total 12 dyads who lived by themselves, among which 2 Dyads had no children, 6 Dyads with children living in other cities or overseas and 4 Dyads with one or more children living in the same city and others in another city or overseas (among those 4, 2dyads had son and other 2 had daughters).

The above result throws light on the trend of children moving to other cities and countries in search of better opportunities which created new kind of families comprising of old couples alone. There were also other types of arrangements observed where a sibling played the role of a caregiver. There was only one older widowed woman who lived with her married daughter in her house which largely remains a taboo as per conventional social beliefs.

**Table 2***Marital Status of the Participants*

	Married	Unmarried	Widow
<b>Men</b>	22	-	-
<b>Women</b>	22	-	6

Table 2 shows that all the men participants were married. Among the women participants 22 of them were married and 6 of them were widows. Married couples identified as caregivers for each other irrespective of their living arrangements.

**Table 3***Religious Distribution of the Participants*

	Hindu	Muslim
<b>Dyads</b>	13	12

Table 3 shows that there was almost equal representation of two major religions which were, Hindu and Muslim.

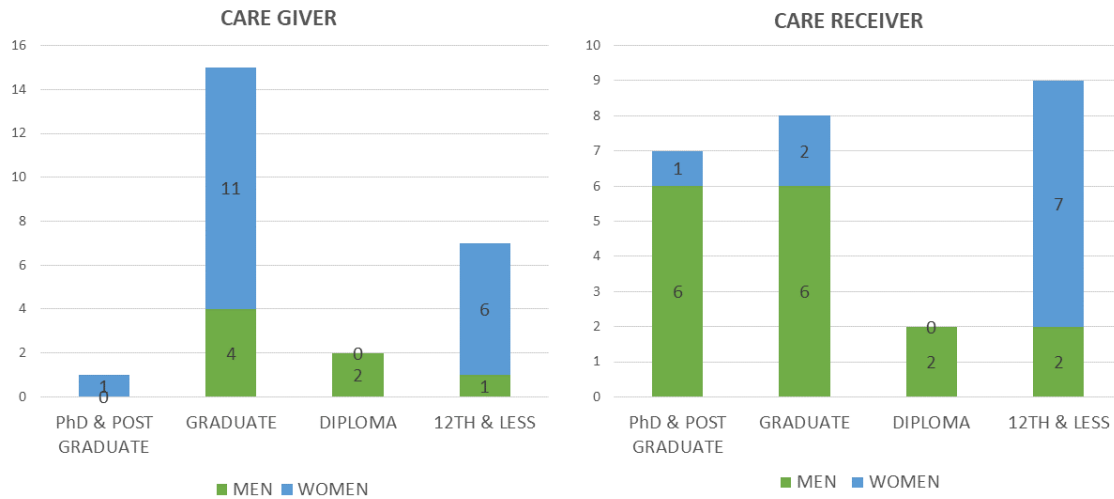
**Figure 5***Level of Education of the Participants*

Figure 5 shows the educational qualifications were higher in men than in women and majority of care receivers were men. Since this data is of older persons, it shows the trend of differences in educational opportunities especially for higher education was available to men versus women. Some of the women participants talked about lack of family support and opportunities for their higher education in their young age. They shared that the expectations were from them to be good caregivers and manage families than pursue careers.

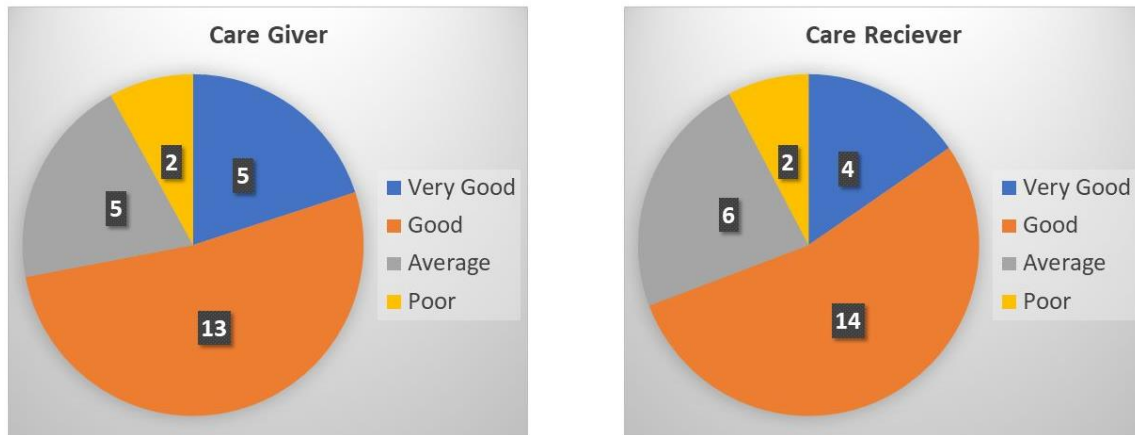
**Figure 6***Self-Perception about Health among the Participants*

Figure 6 determines that majority of the participants across caregivers and care receivers group perceived their health status to be good or very good. Almost equal number of caregivers (7 participants) and care receivers (8 participants) perceived their health to be average or poor. More caregivers reported of having no issues than receivers.

These results indicated that self- perception of health was not an important criteria for identifying as or assuming the role of caregiver or receiver. Also, caregiving was not understood as limited to physical care giving or assistance. It covered important aspects of emotional support, financial and decision making support and even one's own understanding based on social and cultural expectations.

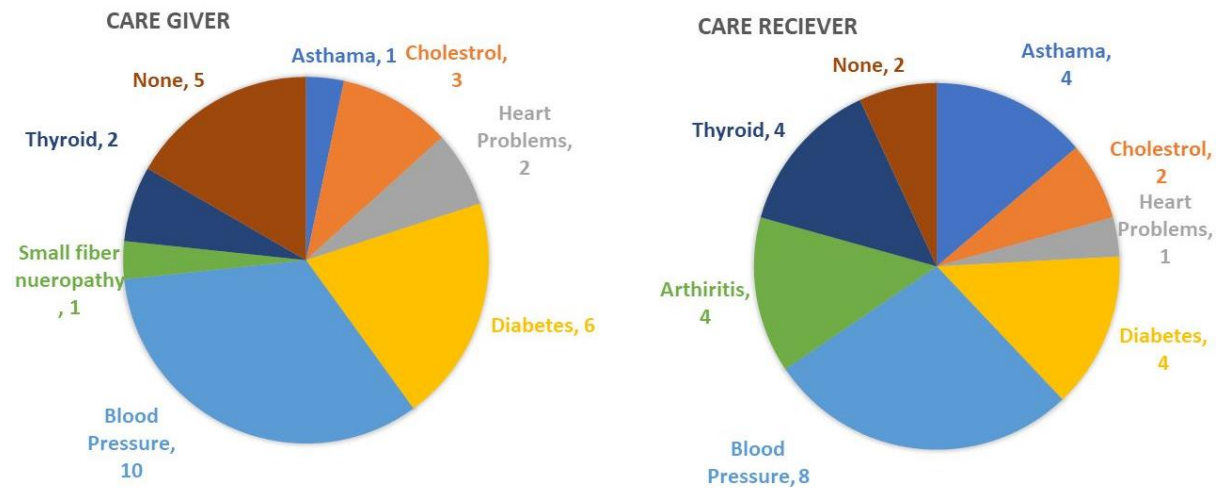
**Figure 7***Health Issues Reported by the Participants*

Figure 7 indicates that both caregivers and receivers reported of suffering from chronic health issues such as blood Pressure, diabetes, thyroid diseases, cardiac disease of which diabetes and blood pressure were the most common condition affecting the health of the participants. Infact, these conditions were reported more by caregivers than care receivers. Arthritis was reported only by the care receivers (both men and women). Asthma and thyroid diseases were also more commonly reported by care receivers. More caregivers reported of having no issues than receivers.

**Table 4***Financial Dependency Status of the Participants*

Dependency	Caregivers (n=25)		Care receivers (n=25)	
	Men (n=7)	Women (n=18)	Men (n=15)	Women (n=10)
Independent	5	2	10	1
Partially Dependent	2	2	2	3
Totally Dependent	0	14	3	6

Table 4 indicates how care receivers were more self-reliant for financial needs than caregivers. While the maximum numbers of care recipients were men, the majority of them had different sources of income such as income from their businesses, part time jobs or pension. Fewer participants were totally dependent on family for their financial needs. Number of caregivers who were completely financially dependent was higher compared to care receivers.

Several women participants shared that there was not much familial encouragement or support for them to work in their younger days, therefore they were now reliant on others. As expressed by one of the woman (Caregiver) ***“iccha to bau hati ane degree pan hati par shadi pachi javabdaari aavi etle koi e parvangi naa aapi”*** ( *I really wanted to(work) and even had a degree but due to responsibilities after marriage, the family did not give permission*). Another woman said, ***“ Teaching no mane bau shok hato, hato su aaje pan che, aa mane (referring to her husband) kaam nai krava didu pan hu mara bachao na bachao ne bhanau chu”***( *I was really fond of teaching, even today I am, but as my husband did not agree I couldn't work, although today I do teach my grandchildren*).

This result indicates the stricter and more traditional gender role expectations among participants and experiences of women 40 or 50 years ago. It also suggests that the families insisted on them assuming the care giving roles in their young adulthood and these roles were strongly internalised by them and they continued to play those roles into their later lives as well.

**Figure 8**

*Socio Economic Status of the Participants*

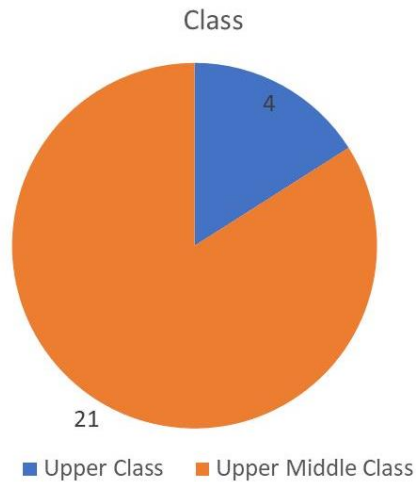


Figure 8 shows that all the participants belonged to upper middle and upper social economic class as per Kuppuswami scale. The majority of them belonged to upper middle class and 4 dyads belonged to upper class. Kuppuswami scale was used to determine the socio-economic class of the participants, which gives a composite score of education and occupation of the head of the family along with monthly income of the family.

## Section 2

### Living and Caregiving Arrangement

This section discusses the following aspects of the caregiving.

- Tasks by caregiver for care receiver
- Typical day routine,
- Time spent together by caregivers and receivers
- Paid help/ formal care
- Availability of support in absence of the main caregiver

**Figure 9**

#### *Tasks by Caregiver for Care Receiver*

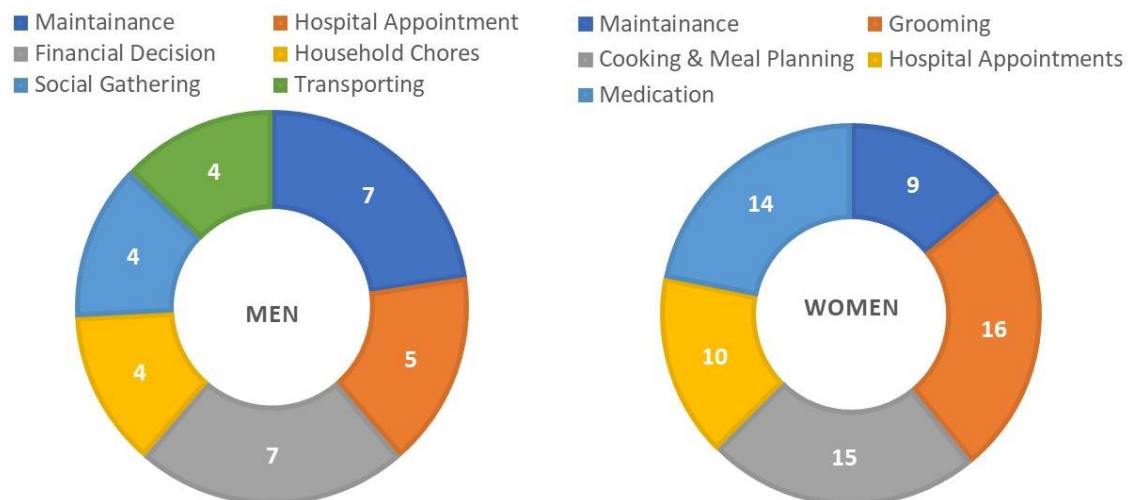


Figure 9 depicts the various tasks performed by caregivers for the care receivers. Gender based distribution was visible here, as in the majority of the cases women were the caregivers and participants were found to take care of their spouses in terms of cleaning and house upkeep, cooking, meal planning, medicine administration, medical visits, and assisting



in self-care. While men caregivers primarily took care of their partners in terms of financial decisions, purchasing necessary items, medical visits, transportation, and attending social functions. Although there were some exceptions where men participants did household chores such as cooking, washing utensils and clothes, cleaning, and house maintenance because of their wife's physical health and these exceptions were only found in the dyads who were living all by themselves. One of the man participants said, *"hu pote badhu kari lau chu, vasan dhova na hoi ki kapda, jaatej dhov chu, khavanu nu pakavta aavde che"* ( I do everything on my own, whether it is washing utensils or clothes, also I can cook food).

Apart from being the caregivers, older persons living with families also shoulders a variety of other responsibilities like: taking care of grandchildren in the absence of their parents (when men and women both were working) as well as assisting with the household chores.

**Figure 10**

*Typical Day Routine of Caregivers*

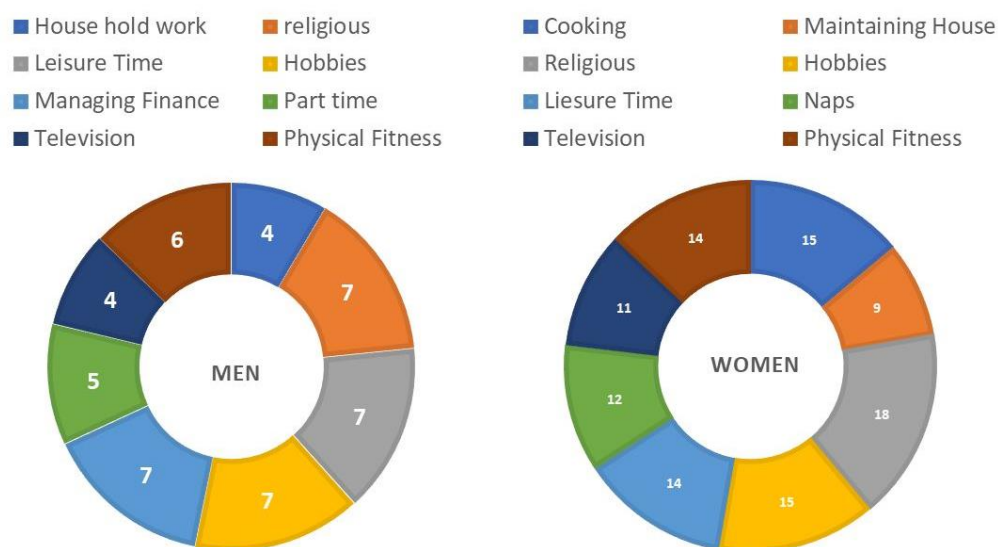


Figure 10 depicts the caregivers' daily routine. First, the image depicts the routine of men caretakers, in which the majority of them spend their time managing household finances, pursuing hobbies (things they enjoyed doing) or recreational activities like watching television, exercising, spending time with family and friends, activities for being physically fit and participating in religious activities. Four out of the seven men dedicated themselves to doing housework and many of them continued to work part-time even after reaching the retirement age.

Women spend the most of their time participating in religious activities, pursuing hobbies, spending time with family and friends, staying physically fit (maintaining proper diet, exercising, yoga), watching television, cooking for the family, and napping. Gender roles are clearly obvious in this category as well, with the results indicating that men caregivers are mostly involved in house finances and completing their jobs. Few of them participate in family tasks. Women, on the other hand rarely reported of being involved in financial decisions. The primary aspects were cooking and housekeeping and providing care to family members.

As it is evident from the results above that most caregivers were able to have some time for them and were not too tied to caregiving, this was because majority of the care receivers enjoyed good health status and were able to perform the Activities for the Daily Living. There was not much physical assistance required and availability of domestic workers was available which reduced their burden.

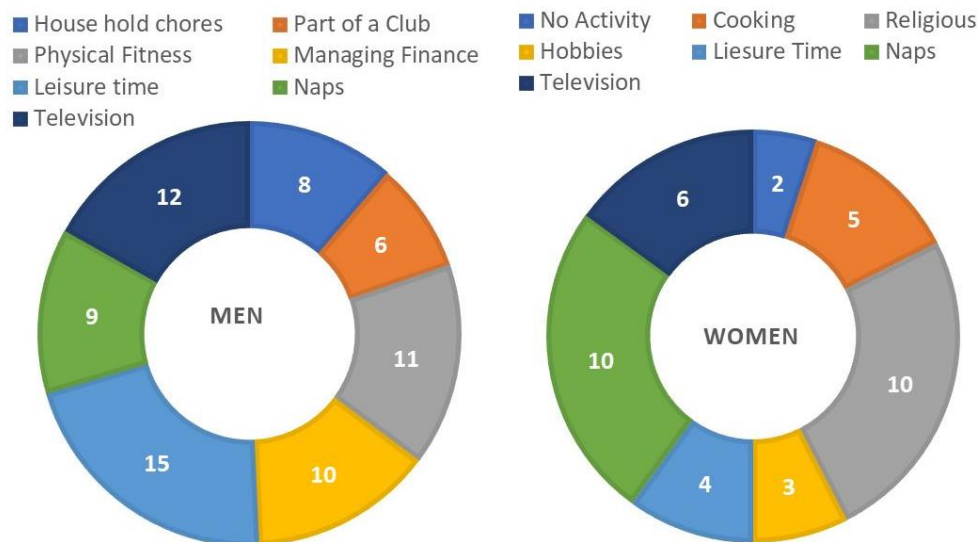
**Figure 11***Typical Day Routine of Care receivers*

Figure 11 depicts the care receivers' daily schedule. The men care receiver's routine is first illustrated, in which the majority of them spend their day socializing with friends and family, watching television, exercising, and managing finances. Few of them spent their time doing housework, napping, or participating in clubs of older people.

Due to their age and physical limitations, two women care recipients did not participate in any activities at all. Others spent their days participating in religious activities. Care receivers were not very active in household work.

**Number of Hours Spent Together**

As the majority of the older persons who identified as care recipients did not experience too much physical dependency, caregivers were not bound by caregiving in terms of much of physical assistance. The time spent together was more of companionship and emotional caregiving.

Because the majority of participants were dyads living alone and retired, they spent the majority of their time together, helping each other with household tasks, eating together, socializing, and so on. While there were men participants who were still engaged in economic activities, they used to contribute a few hours or half of the day to their work while spending the rest of it with their partner. The other group of participants, who were living with their children/family, used to spend comparatively less time with their spouse than the dyad living alone (without family), because their time got distributed among the other members of the dyad and responsibilities such as grand parenting.

Due to availability of spouse in case of couples living alone and availability of children and grandchildren or even married daughters living in the same city, participants did not feel isolated or lonely. Another factor that acted in support of the older persons was the availability of support in terms of assistance from domestic support workers on part time or full time basis.

**Figure 12**

*Paid Help/ Formal Caregiving*

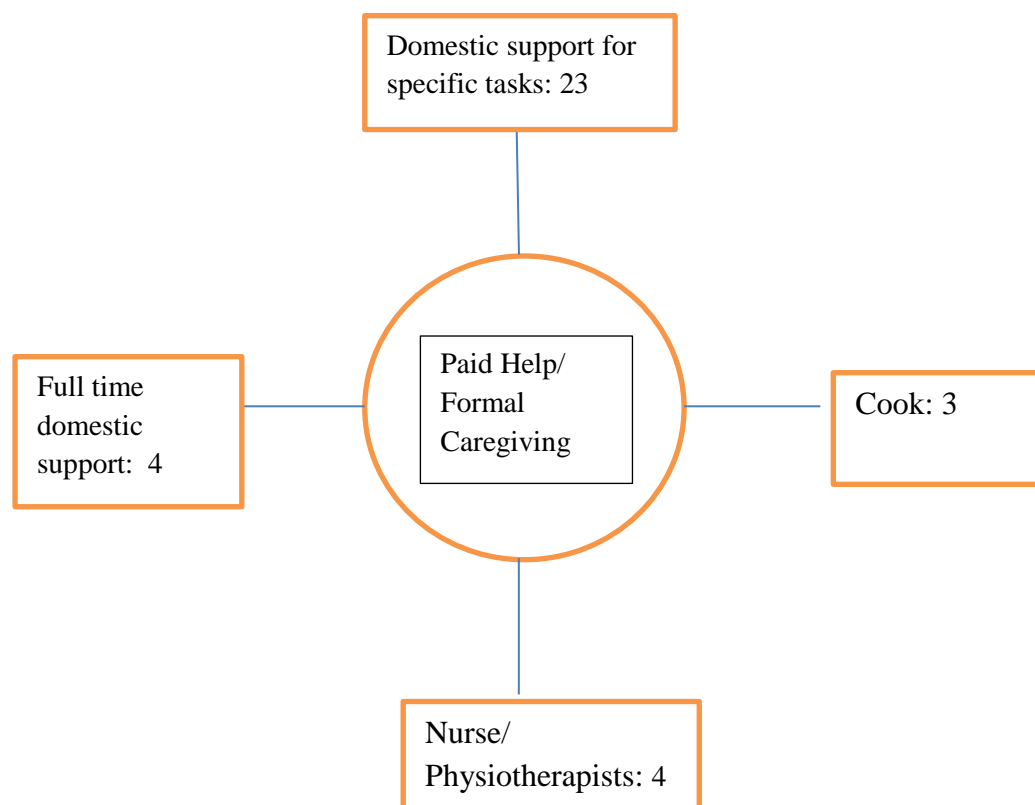
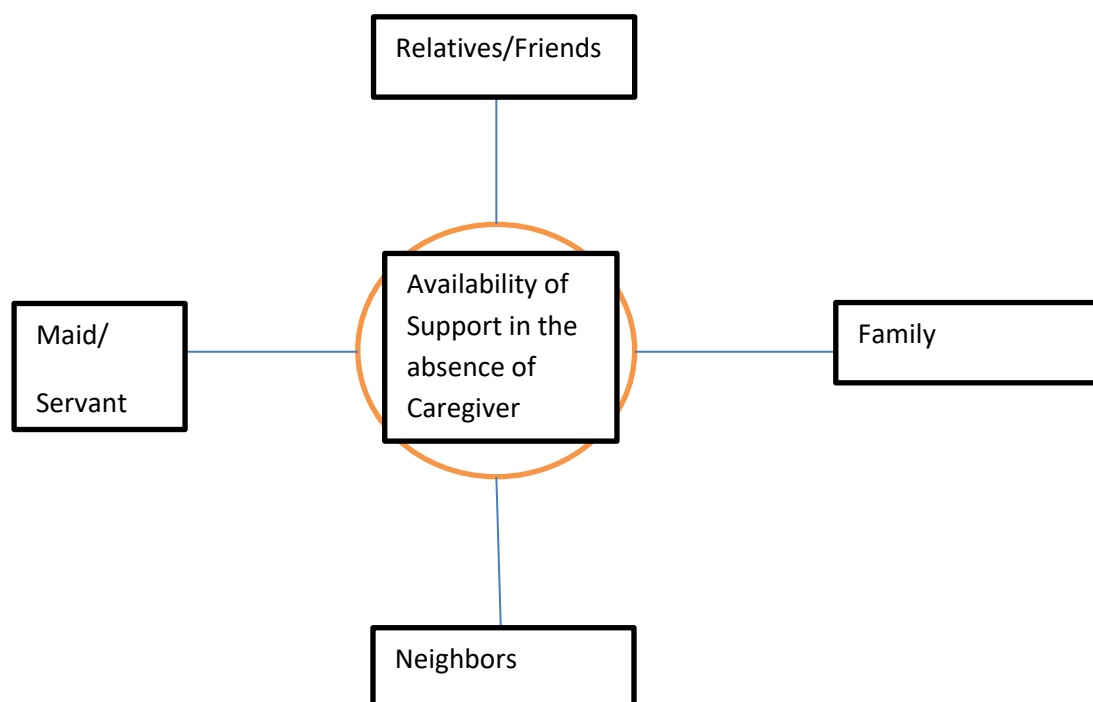


Figure 12 shows that the participants relied on domestic helpers for cooking, housekeeping and other tasks.

Although none of the participants were availing services of the formal carers at the time of the data collection, some families had availed home based services of full time/ part time nurses or physiotherapists in cases of health issues/ accidents/ falls and short spans of temporary disability. It is noteworthy that the participants belonged to upper middle and upper socioeconomic status, they had sufficient means to avail paid help and formal caregiving facilities which helped in avoiding additional challenges that families would encounter.

**Figure 13**

*Availability of Support in the Absence of the Main Caregiver*



**Figure 14**

*Areas where Help is required or given*

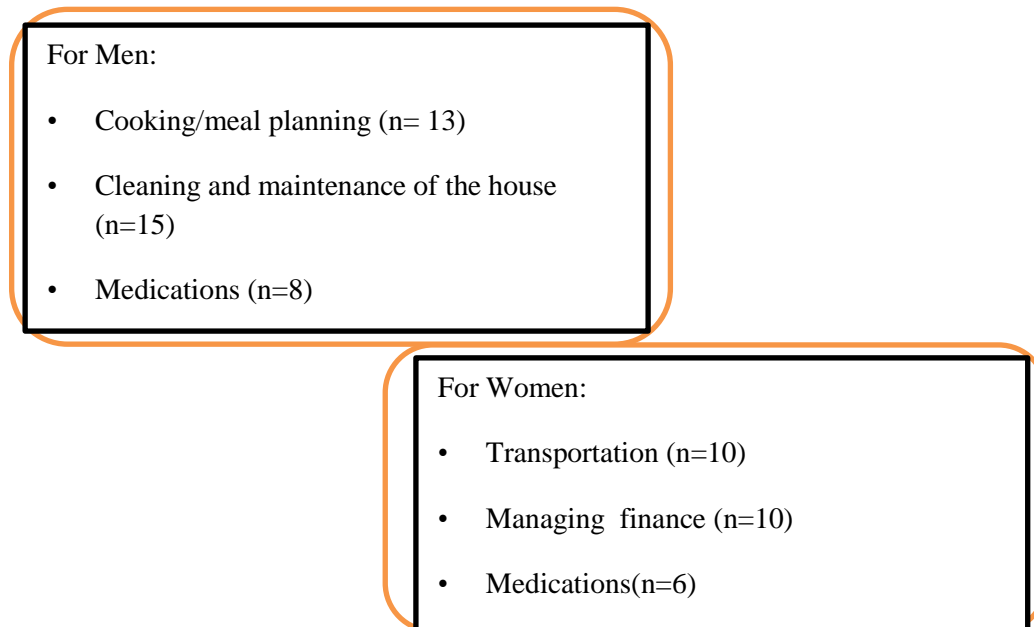


Figure 13 and 14 shows that out of 25 caregivers, 23 stated that the care recipient is self-sufficient to care for himself/herself. Thus they were able to manage without much difficulty in case the caregiver was not available for a few days. In the case of men, the only thing they needed help with in absence of caregivers was food, which was provided by other family members, neighbors, servants, friends or relatives. When questioned about other carers, participants who lived in a joint household mostly said other members of the family and maids of the home who take care of the care recipient (men) in terms of cooking or medicine, cleaning and keeping the house. Women care recipients are cared for by assisting them with transportation, obtaining items from the market, and handling finances.

Participants who lived alone with their spouse normally had no one nearby for caregiving other than the primary caregiver, but in the event of an emergency, they had family, friends, and neighbors to help with food, transportation, and bringing products from the market.

### Section 3

#### Issues and Challenges

This section includes issues and challenges faced by the participants especially in relation to caregiving or care receiving.

#### Figure 15

##### *Issues and Challenges of the Dyads living by themselves and with Family*

The majority of participants did not report experiencing many challenges and the main reasons were comparatively better health status of the care receivers and care givers, access to social support from extended family members, friends and relatives as and when in need. They also had access to paid formal care. Thus, even in a challenging situation, it was easier to manage. Despite this, some of the challenges faced were as shown below.

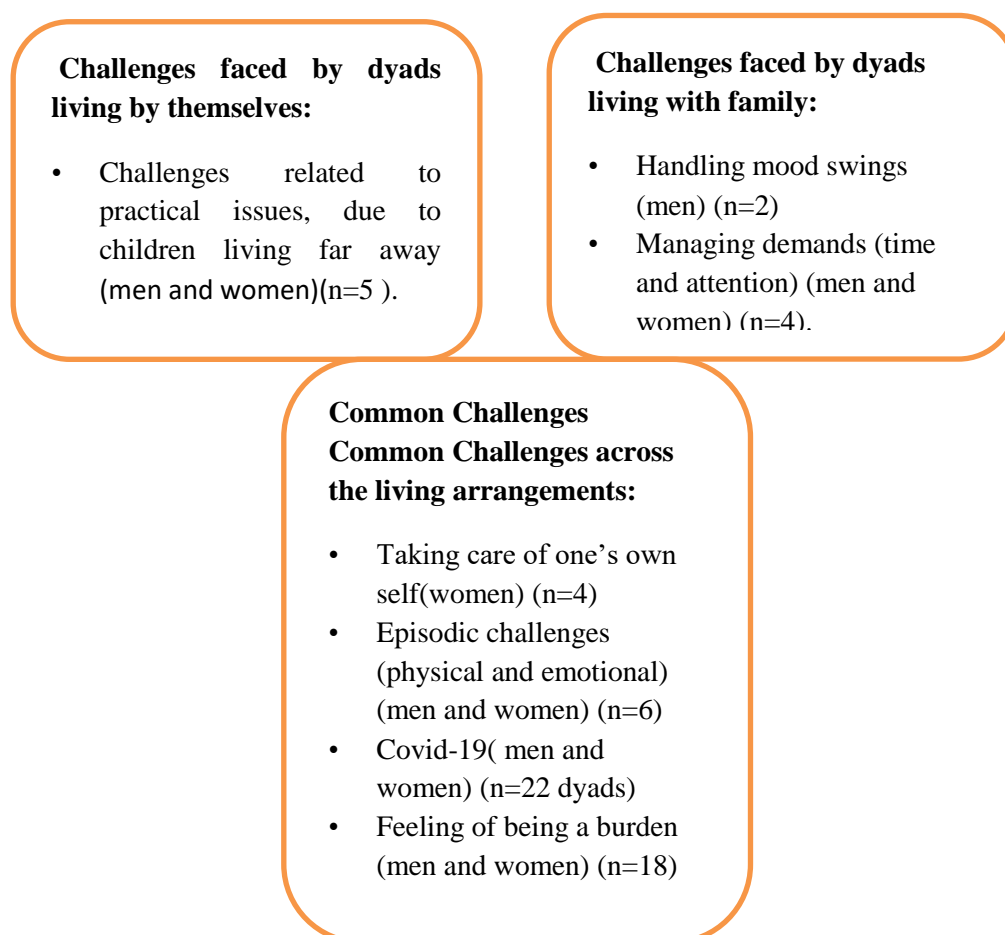


Figure 15 depicts various issues and challenges faced by the caregivers and care receivers.

**Common issues faced by dyads irrespective of their living arrangements were:**

- In sufficient time and opportunities for self-care – Some caregivers reported that it was challenging to take care of their own self as they prioritized needs of the care receivers and did not focus on self as much as they would have liked. Some of the care givers felt that their declining physical health was a major challenge as they could not do as much. This also led to emotional exhaustion at times.
- Most participants reported of facing several challenges at the time of Covid-19, a couple of years ago and dyads living alone experienced greater challenges because they lacked extra assistance during the pandemic. They discussed the times when they were both hospitalized and had no one to take care of them. As one of the older man expressed *“Covid to bau kharab samay hato, ne hamara banne ne ekj time par thayelu ane sathej dakhil pan thayela ane dhyaan rakhnar koi na male”*( Covid was a very bad time and we both tested positive at the same time , together we got hospitalized but there was no one to look after us).
- Some of the participants felt that their feeling of being a burden on children was their personal challenge. Interestingly, this feeling was reported by both kind of dyads, living alone or living with families. Possibly this feeling was more associated with perception of one’s declining physical, emotional or financial strength and independence.
- Some men living with their spouse and family expressed that it sometimes got difficult for them to handle their wives mood swings. This challenge was reported only by men as



they felt that they struggled to understand and respond to the emotional needs of their spouses.

- Another challenge was about balancing between the demands of the care receivers and other members in the family in terms of giving time and attention. One of the married daughter who was a carer for her mother expressed that ***“it really gets difficult to distribute time between my mother and husband, baa sathe akho divas rahv, due to her health issues, to my husband gets a bit upset”*** (If I spend time with my mother the entire day, due to her health issues, my husband gets a bit upset).

Challenges reported by older couples living alone were relating to physical distance of their children as they thought that having children around would have made many things easier. As one of the woman participants living with her husband expressed, ***“Takleef to khaas laagti nathi, aadat thai gayi che have badhu jaate karvani, par haa evu thai ghani vaar ke bacahao sathe rehta to hardmaari ochi thaat”*** (there aren't many difficulties, it has become a habit now to do everything on our own but yes sometimes it feels that if my children were living with us, there might be lesser difficulties.)

As the entire participant group was financially and socially well placed, they did not face many challenges in terms of resources. The nature of challenges was more emotional in nature such as prioritizing one's on needs or balancing between the needs of family members. Managing the moods of the care receivers, especially women was found challenging by men. Physical distance from their children was seen as a challenge by some of the participants despite their ability to manage everything on their own.

## Section 4

### Impact of Caregiving on Caregivers

This section includes the positive and negative impact of caregiving on caregivers and the impact on the relationship with spouse over the years and now.

**Figure 16**

*Positive and Negative Impact on Caregivers*

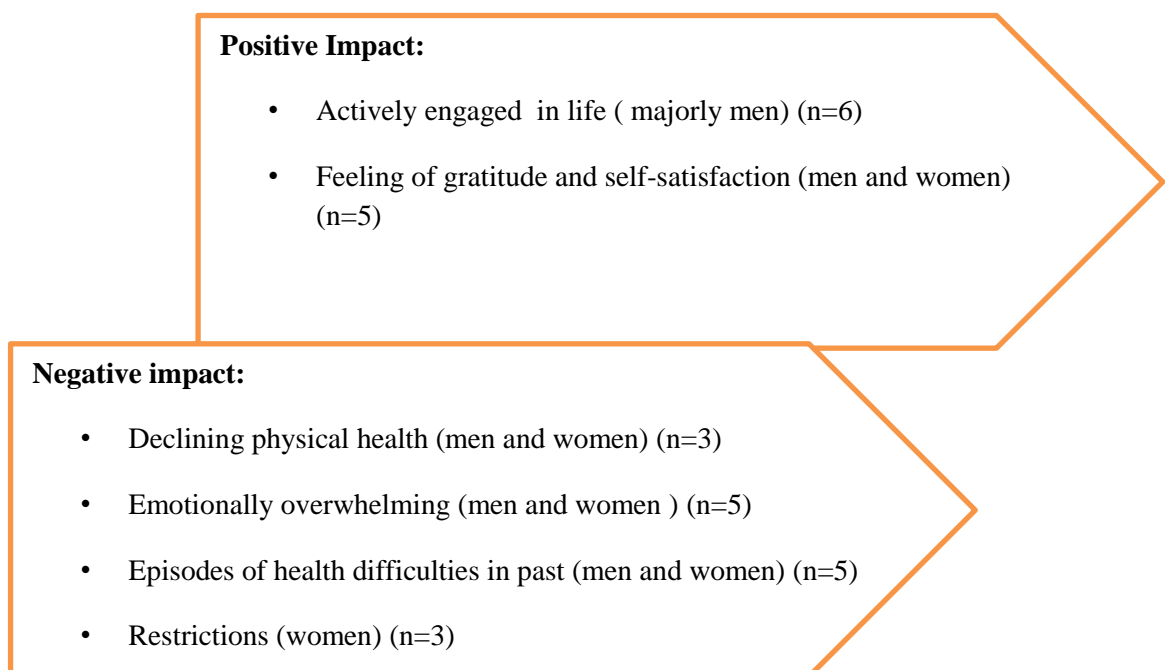


Figure 16 depicts various positive and negative impacts on Caregivers.

Majority (18) caregivers did not perceive any negative impact of caregiving on themselves. Most participants looked at their role as caregivers quite positively. As it is clear from the data, none of the care receivers were completely dependent on caregivers as by far most of them enjoyed good health despite having chronic diseases. Their role as a caregiver revolved more ensuring provision of requirements, overseeing arrangements and emotional care and companionship. The task of caregiving did not involve exhausting routines or physical exertion which was a positive factor that avoided negative impact on physical,

emotional or relational impact on caregivers. One of the man participants said, ***“ehvu kai khaas dhyaan rakhvu padtu nathi, jethi kai apna par asar pade”*** (*I really don't have to take much care, that could have any impact on me*). A lot of the older persons expressed that being so active at this age made them stronger and resilient. They felt they were meaningfully engaged. Based on researcher's observation and interaction with the participants, it was interpreted that many of the caregivers, individually acknowledged their sense of satisfaction and gratefulness for being able to be with partner, parent, or sibling.

Comparatively smaller number of men and women reported of any sort of a negative impact. Five caregivers stated that sometimes they felt over- burdened and overwhelming due to responsibilities. They also indicated that they would like the partner and other family members to share the responsibilities. As one of the woman participants expressed by saying ***“koi koi vaar ehvu laage e haji ketlu karvu padse, haji ketli javabdari poori karvani baaki che. Thodi javabdari ehme pan to male ne”*** (*sometimes it feels overwhelming and feels about how many more responsibility do I have to take, he should also get some responsibility*).

Only three participants, all women talked about the physical impact felt by them in terms of impact on their physical health like aches and pain or physical emotional fatigue. One of the woman participants said, ***“pehla jyare ehme hospital ma rakhela tyare bau thaki javatu tu, mara pan ghootan ma takleef rehti”*** (*in the past when he was admitted in the hospital at that time I used to get very tired I used t have difficulties with my knees*).

Although there were not many factors present during the time of data collection that would create negative impact on the caregivers, some of them shared about difficulties faced in the past. These were the impact in terms of emotional exhaustion and tension due to health issues of the partner.

A couple of women shared about feelings restricted due to the need for keeping one's self available for the care receivers which restricted their physical mobility. This had an impact on these women's social visits or overnight stays beyond a point.

### Figure 17

*Impact on the Relationship with Spouse over the Years and Now*

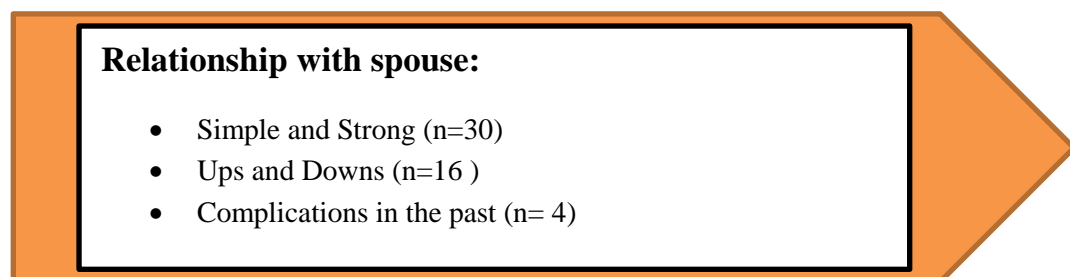


Figure 17 depicts the impact on the relationship with spouse over the years and now.

All the participants gave a mixed answer in which they said that right now their relationship is sweet, simple and strong, but there are times where in there are ups and down, which is common in every relationship. One of the participants also mentioned that there were times their relationship/marriage was about to end, but due to elder's wise decision and guidelines they got back together and now everything is on track and they are happy together. The participant further said that how important is for the couple to hold on and bounce back every time some difficulty arises. Also some participants mentioned how caregiving have brought them more close to each other and how their relationship has grown stronger. On the other hand there were participants who felt distant from the other one as they think that her questioning may be perceived as intrusion to her son.

## Section 5

### Views and Experiences of caregivers and care receivers

This section talks about views of the participants on various aspects of caregiving to the older persons including different qualities a caregiver should have, advice to other older persons, sense of satisfaction with life, thoughts about future, motivations for caregiving, views on care for older people in contemporary society as well as life experiences of caregivers and care receivers,

**Figure 18**

*Qualities a Caregiver should have*

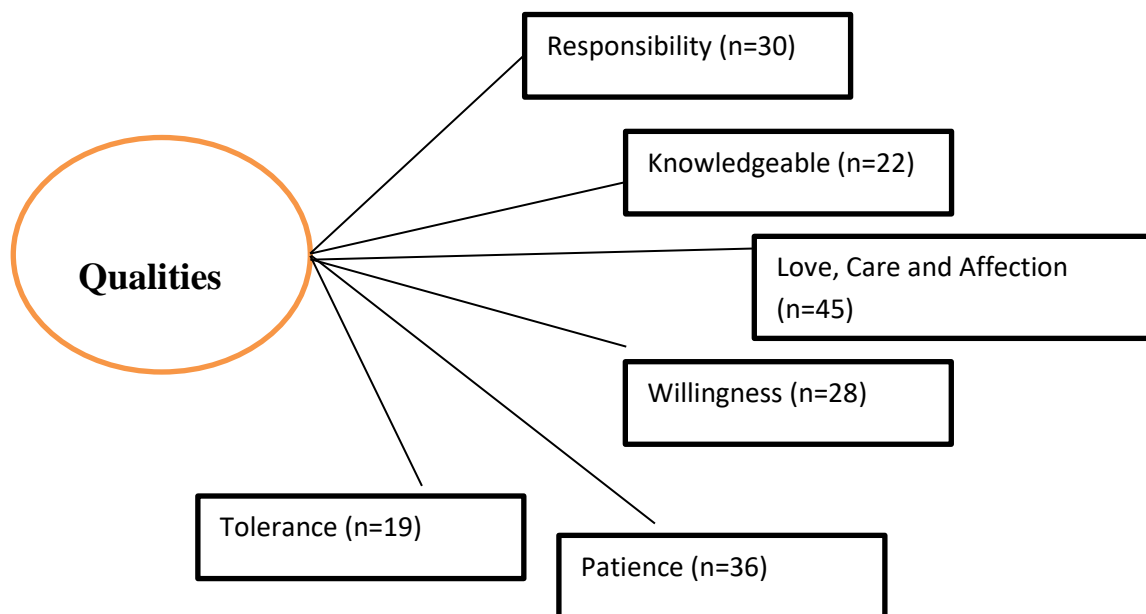


Figure 18 shows the different qualities a caregiver should have according to both the caregiver and receivers

**Responsibility**

One of the themes that emerged was sense of responsibility; with participants expressing that one of the most important qualities a caregiver taking care of an older person should be to be responsible and dependable. It was expressed that caregivers should be well aware of their duties and roles.

**Knowledge**

Knowledge emerged as another important attribute in qualities of good caregiving. Several participants felt that without sufficient knowledge and understanding, one would not be able to care for elderly people and their needs. Hence, in order to be a good caregiver, one must first learn about the caregiver's needs and desires. The participants were not referring to technical knowledge but instead focusing on knowing the care receiver well enough to understand their needs.

**Love Care and Affection**

Love, Care and Affection was another factor which the participants felt was important for caregiving of the elderly. The emotion of love, care, and affection is the most vital to have when caring for the elderly, because only through these sentiments would one be able to offer their all and make the elderly's life simpler and happier.

**Willingness**

Another important theme which emerged was willingness, where in participants said that nothing can be done without willingness. Caregiving cannot be done effectively until and unless the caregiver has the desire to care for the other person.

## **Patience**

Patience was another factor which the participants felt was important for caregiving of the elderly. It is essential when dealing with the elderly. It is critical to maintain cool and handle everything with patience. There may be moments when one loses their cool due to the conduct of an elderly person, but being patient and calm is essential for efficient caregiving.

## **Tolerance**

As per the participants, tolerant was also one of the important aspect of caregiver's conduct.. Tolerant capacity is required for some geriatric behavior. Hence, in order to care for the elderly, one must be able to tolerate their behavior, the participants expressed.

## **Expectations of Care receivers**

In response to the question about care receiver's expectations from the caregivers, a range of responses were received from stating that there was no need to have any expectations as the caregiver understood them very well and fulfilled all their needs, to the other end of the spectrum that talked about the attempts of reducing expectations or having no expectations at all to avoid disappointment of any sort.

Majority of the care receivers received care from spouse and they felt that their needs and wellbeing was understood by them very well, thus there was no scope for any other expectations.

Three care receivers expressed that they would like if their caregivers could spend more quality time with them. One of the woman participant who was a widow living in a multi-generational family, who identified her son as her primary caregiver expressed that she would like her son to spend more time and share with her about things that were happening

with him, but at the same time she expressed that she understood that her son who was also living a retired life had his own life and priorities so there was nothing to complaint about.

Although the question was pertaining to the primary caregivers some of the care receivers also related this question with their children as they talked about importance of working on minimizing or absolutely not keeping any expectations to protect oneself from disappointment. As one of the older man who was a care recipient stated *“khush rehvano ek tareeko che, aasha nai rakhvani koi thi, aasha hoi nai ane dukhi thau nai”* (to stay happy, you should have no expectations from others. Having no expectations will never hurt you).

It was also interesting to note that most of the participants talked about minimising expectation in a very balanced and positive manner, expressing that they understood that the children had their own life and work related pressures and parents needed to understand that. Most parents whose children were abroad or in other cities expressed that they were happy about their children doing well and thus had not many expectations or complaints with them with regard to their own care but deep down every one of them were a bit dissatisfied as their children lived far away and desired to have them nearby. Some of the other reasons why older persons preferred to stop expecting much from children were their own preference to live an independent life, protect one's dignity and ensure that they do not become burdensome on anyone. They also shared that they wanted to ensure that they do not interfere in anyone's life and give everyone their own space.



**Figure 19**

*Advice for Older People by Caregivers and Care receivers*

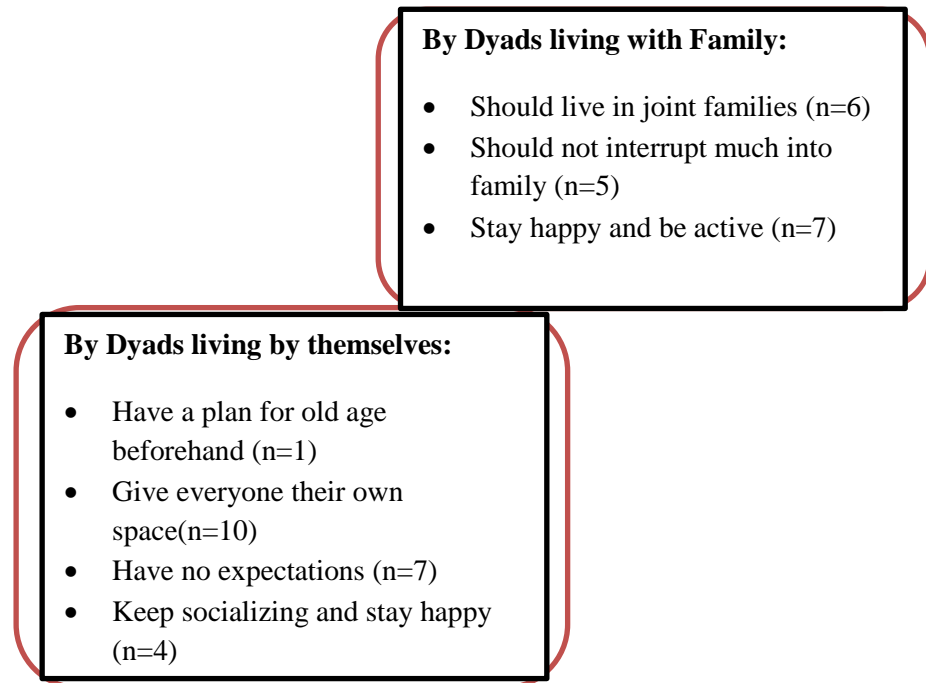


Figure 19 shows the various advices given by the participants to older people. When asked to give an advice to the older people, dyads living with family expressed their views by saying that people at this stage should live in joint families but should not interfere much in their family for a happy life.

When same question was asked to dyads living by themselves, participants expressed their views by saying that people at this age should not get much involved in the families of their children. One the of the man participants expressed his concern towards the older people by saying, people at this age should try and be as independent as possible and for doing so they should plan everything since their young days about their later life at this age. Also few participants mentioned that in order to live a peaceful life one should have no expectations

from others. None of the dyads here advised living in joint families, despite the fact that they always want their children to stay with them.

There appeared to be a balancing act between the emotional expectations and acceptance of reality. Because most parents were happy and proud of their children's achievement and hoped for better future of their children, they did not mind the distance from the children. Availability of distant care also seemed to make things easier. However in earlier topics related to challenges, some of them did mention that life would be easier if their children lived with or at least closer to them.

## Figure 20

### *Satisfaction with Present Living Arrangements*

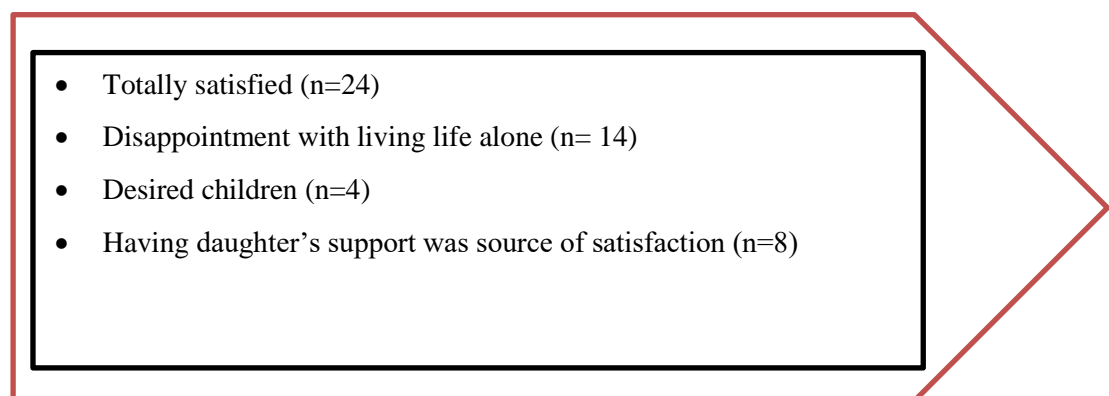


Figure 20 shows how much the participants were satisfied with their lives.

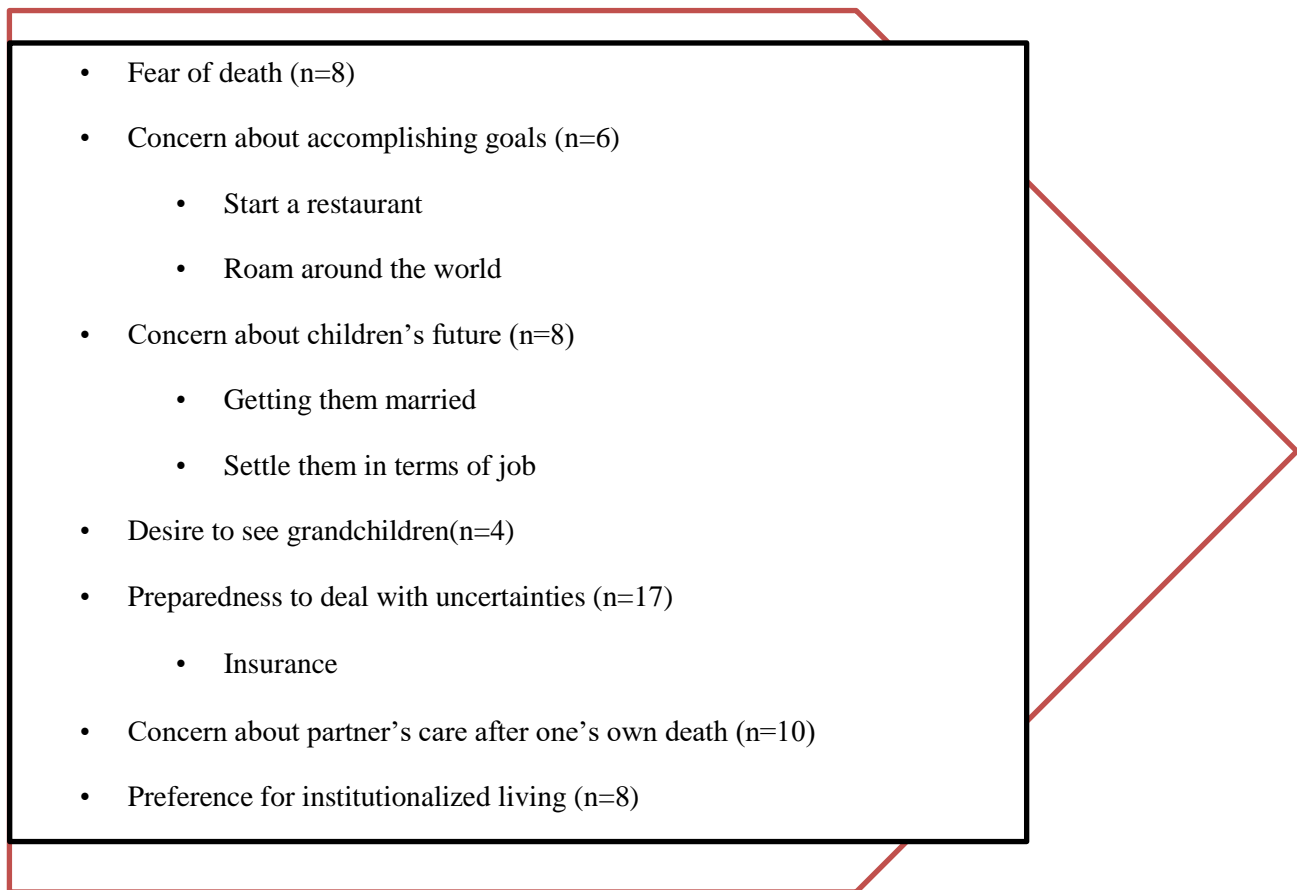
Although a few of them expressed disappointment with living life alone at this age, they wanted their children to be with them, and the couples who did not have children wished that they had children.

Although not related to the question of satisfaction of care and living arrangement, some of the participants talked about other dissatisfactions in their lives which included

making some bad/poor decisions in the past (example career, disrespecting parent's decision). Some women talked about dissatisfaction and regrets for not having jobs or not getting into workforce due to lack of family support.

For some of the participants their daughter (s) living nearby was perceived as a huge support and was found to have a positive impact. Daughters played a major role in their life by giving them care and attention they sought in their own house living with son(s) but missing out on that sort of attention and warmth. One of the woman participants said, ***“10-12 divas hu mari dikri na tya rahi aavuv, dikri nu to tame janoj cho, juduj hoi che”*** (for 10-12 days I go and stay at my daughter's, you know about daughters, its different). Another woman said, ***“hamari dikri aiya najik maj reh che, etle sanje aavi jai aiya ane pachi raate jaminej jai”*** (we have our daughter living nearby so every evening she come here and leaves only after having dinner with us).

Having a daughter who lived in the close vicinity and to be able to have the daughter visit them more often or to be able to visit her was looked up as a great source of support and emotional well-being for the older parents. Emotional connect with daughters and emotional care from daughters emerged as an important theme from the responses.

**Figure 21***Thoughts about Future of the Caregivers and Care receivers*

One of the major concerns which was predominantly reported by couples living by themselves was about concern about partner after one's death. These couples were the best support of each other and their togetherness was the significant source of their resilience. Some of the participants expressed worry about care and wellbeing of their partner after their own death. Avoiding dependency on children emerged so strongly that some of the participants stated that they would prefer to live in institution after death of one of them instead of being dependent on their children, One of the man participants said, "*Hu to ehne kai didu che, ki agar hamara banne mathi jhe pan pehla upde, to bija ne chup chaap vrudh aashram chalu javanu, bachao ne bilkool takleef aapvani nai*" (I have already told her that from 2

*of us whoever will die first, the other should move to old age home. None of us should bother our children).*

Planning and preparation for future uncertainty was another aspect of thoughts about future. Majority of the dyads reported of having health insurance/ life insurance as preparedness for future uncertainties. There were some dyads though who were not in favor of insurance owing to their religious beliefs. It was interesting to note that within Muslim community, getting life/ health insurance was strictly forbidden as they believed that life and death were predetermined and that they could not contest God's judgment by doing so. Although there were some other older persons from Muslim communities who did not believe in this and had adopted more practical approach and availed insurance.

## **Figure 22**

### *Importance of Caregiving for Caregivers*

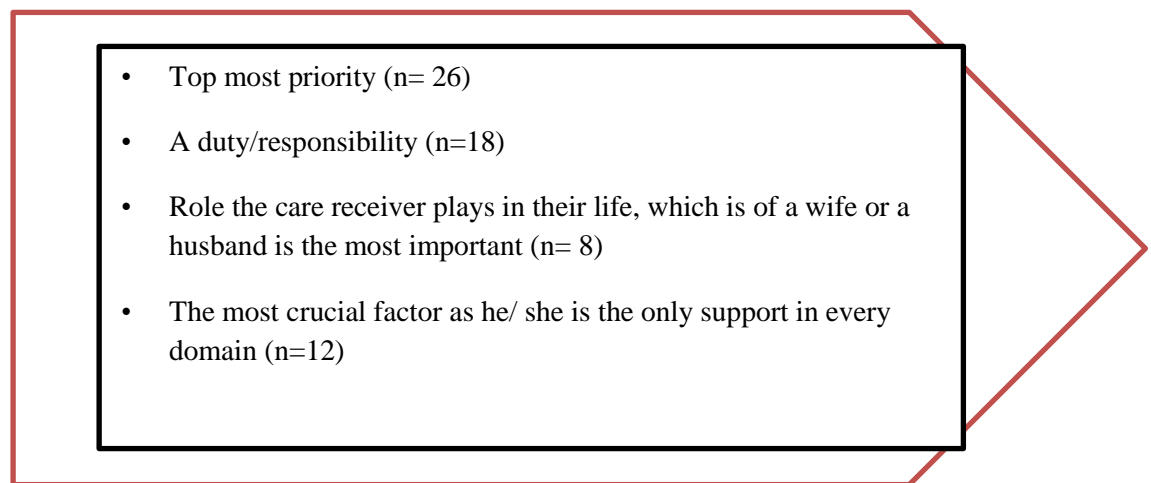


Figure 22 shows the importance of Caregiving for Caregivers.

Caregiving was a high priority for dyads that lived with their families, but some of them also stated that it was more than just a priority to fulfill their responsibility and duty to look after the care recipient. There was nothing more significant in life than being a husband

or wife, where in one of the woman participants said, *“ehmni karta vadhare jarroori su hoi shake che? savthi vadhare jarroori che, ehmnu dhyaan rakhvu.”* (what can be more important than him? To look after him is the most important).

Taking care of the care recipient was the only thing that mattered to dyads living alone since they were the only ones who provided them with their primary assistance in any area, where in one of the man participants said, *“have bhala, hu nai karu to konj karse. Ane pachi ehmnna vagar maru chej kon”* (if not me than who will take care of him and I have no one else other than him).

### Figure 23

*Views on Care of Older People in Contemporary Society ( views of both caregivers and care receivers).*

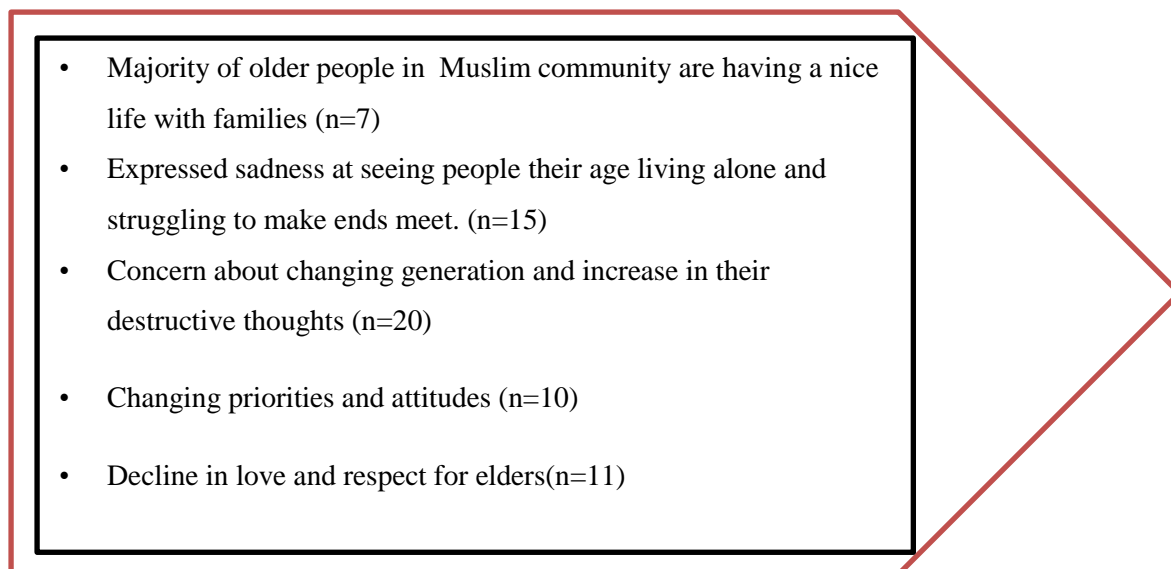


Figure 23 depicts the various views of participants on the topic as whole.

Participants were asked about their views on caregiving trends and concerns in contemporary times.

The dyads living with families felt that majority of older people are living a good life with their family (in a specific community/religion), where in one of the man participants said ***“mara tya koj takleef nathi kem k mara bachao e joyu che ki hume hamara maa baap nu kai rite dhyaan raakhu che, te thi we are getting fruits of it”***(, there are no difficulties in my house because my children have witnessed the way we have taken care of my parents and now we are getting fruits of it), the same participant also said ***“Apna ma ehvu kai thatu nathi, Jova jaiye ne to bahaar nij comn ma aa badha concepts che , vrudh aashram ma rehvana”***(, there is no such concept in our religion(referring to muslim community). If you have noticed these concepts are of people of other communities). One another man participant said ***“hu e bau badha vrudh aashram farya che, ek pan aashram ma hu e mara kom no manas nathi joyo”*** (, I have been to several old care homes, but none of them had people of my community).

But at the same time they also expressed sadness at seeing people of their age living alone and struggling to make ends meet. Some of the participants showed concern about changing generation and increase in their self-centered thoughts, where in one of the woman participants said ***“badhu badlai gayu che, hamara time j alag hato, loko vadhare ane ghar nahnu, have undhu che”*** (everything has changed, during our time there were more people and small house, but now it is the opposite). Another woman said, ***“hamara time ma nahna mohta thi darta, aadar hato, have mohta nahna thi dare che.”*** (during our time, we used to fear our elders and used to respect them and now the elders has a fear of younger ones).

The dyads living by themselves felt that priorities of younger people are now changing. Before, the interests of the family usually take priority over those of individual. But now it's the opposite. There is a decline in love and respect for elders, where in one woman participant said, ***“have to shadi mate pan chokriyo ni list hoi, chokro bahar hoi to pehla puchse ki mane pan sathe lai jase ne, agar chokro naa pade, to shadi naa thai,***

*hamara jamana ma to have ketla varas hamara pati vagar kadya che, saas sasur ni javabdari lidi che”* (, now to get married, a girl has a big list. If the boy is settled abroad, the girl will first make sure that after marriage she also goes along with him and if the boy disagrees with her, the marriage cannot happen. During our time, we have spent a lot of years without our partner and have taken the responsibility of our in-laws.)

Few participants also showed their preference in living in old age homes, after one of them passes away, rather than living with their children, where in one of the man participants said, *“Vrudh aashram ma rehvu is much better, tya tamare badhi sagvad pan male, logo pan saras hoi and bahar ni kach kach thi pan dur”* (which means, to stay in old care home is much better as you get all the facilities, people around are nice and you can keep yourself away from the negative atmosphere).

Although overall the older persons showed positive attitude and acceptance towards children moving out, there were voices of dissatisfaction and discontent with the societal change where they perceived that respect and authority of older persons was reducing. Some people felt that their own communities were better off however older people from other communities were suffering. There were diverse views on care of older persons in contemporary society.



**Figure 24**

*Experiences of Care Givers and Care Receivers*

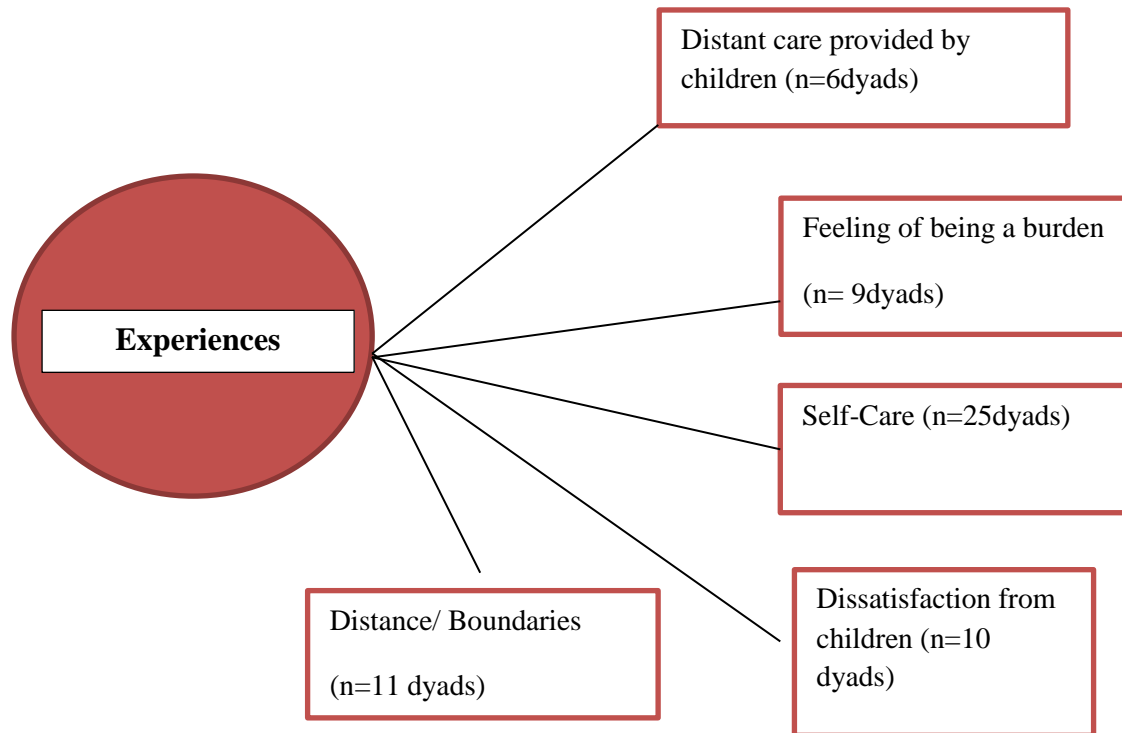


Figure 24 shows the different experiences of caregivers and care receivers.

**Some of the participants though away from their families received distant care in form of**

- Making sure to contact them once in a day
- Visit them once in a year or two
- Asking relatives or others to keep a check on them
- Inviting them at their place once in a year or two.

### **Feeling of being a burden on Children**

Need for self-sufficiency and dignity emerged as an important theme. Feelings of fear or avoidance of being a burden on children emerged in different ways as one of the core concerns of older parents.

### **Self-Care and Hobbies**

The participants took care of and adhered to a few things for their own well-being, including meditation, yoga, exercise, sports, medicine, and food. The participants' replies to questions about their interests included sewing, sports, cooking, music, traveling, gardening, movies, and socializing.

### **Subtle Dissatisfaction**

Although no participants indulged in actively complaining about their own children, there were many comments which conveyed their disappointment from their children especially for their non-availability. They did not blame their children for them and accepted that their children's lives, families and work needed their availability and commitment. At the same time there was this subtle desire for some quality time from their children. Although fewer, some participants showed disappointed with children because they no longer gave them enough time and care as their priorities had changed.

### **Distance/ boundaries:**

Some of the older persons had drawn clear boundaries between themselves and their children. This was seen in couples living by themselves as well as living with families. Although the older persons did not report of any evident conflict or differences with their children, they talked about having fewer expectations, ensuring less interference in children's lives. They seemed to understand that younger generation may have certain liking and

preference which should be respected/ maintained to ensure mutual respect and harmonious relations.

**Figure 25**

*Stereotyped Role Distribution*

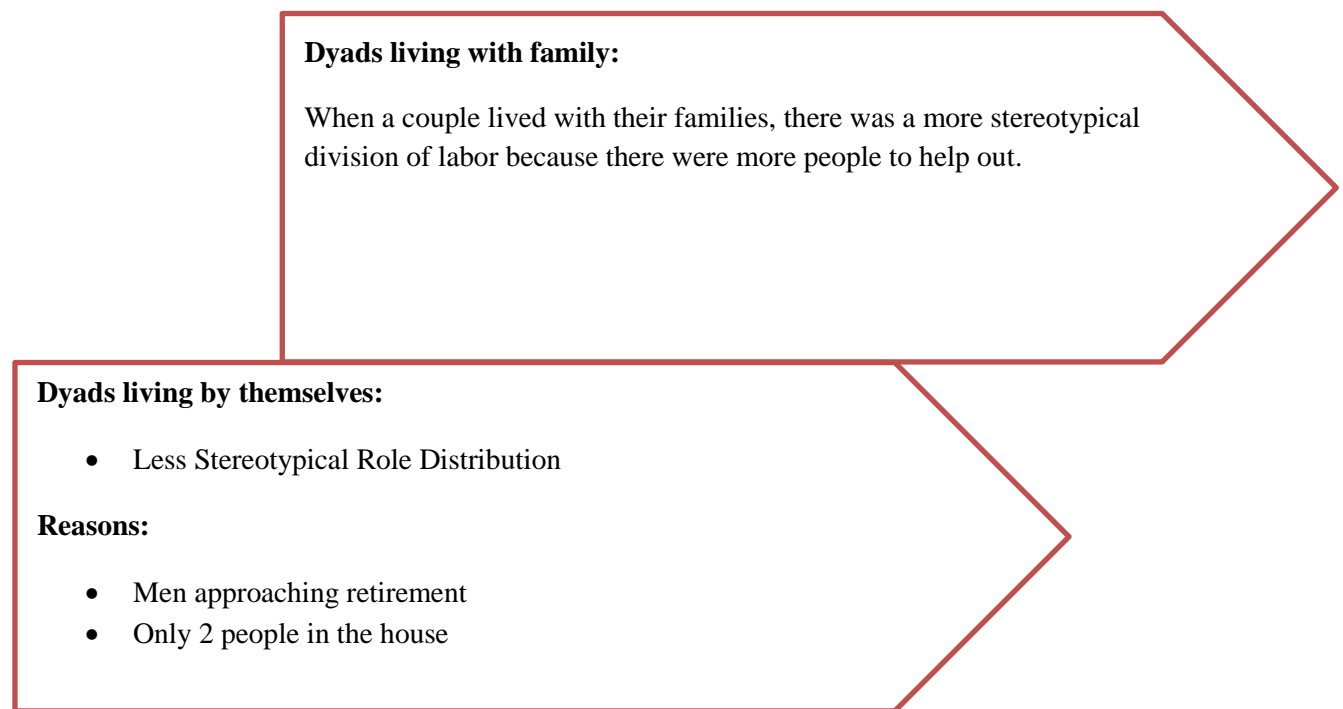


Figure 25 shows the Stereotyped Role Distribution. When a couple lived with their families, there was a more stereotypical division of gender roles because there were more people to help out. For example, the men of the house would never cook or worry about housekeeping when the maid was away because they trusted their wives and daughter in-law(s) to take care of everything.

Due to the fact that there were only two people living together and no other significant support, dyads without family members had a less stereotyped role distribution. Another factor was that the majority of the men participants were approaching retirement. As a result, they used to spend the entire day at home, where men assisted their wives with cleaning and keeping the home.

**Figure 26**

*Views on Gender Roles at this stage*

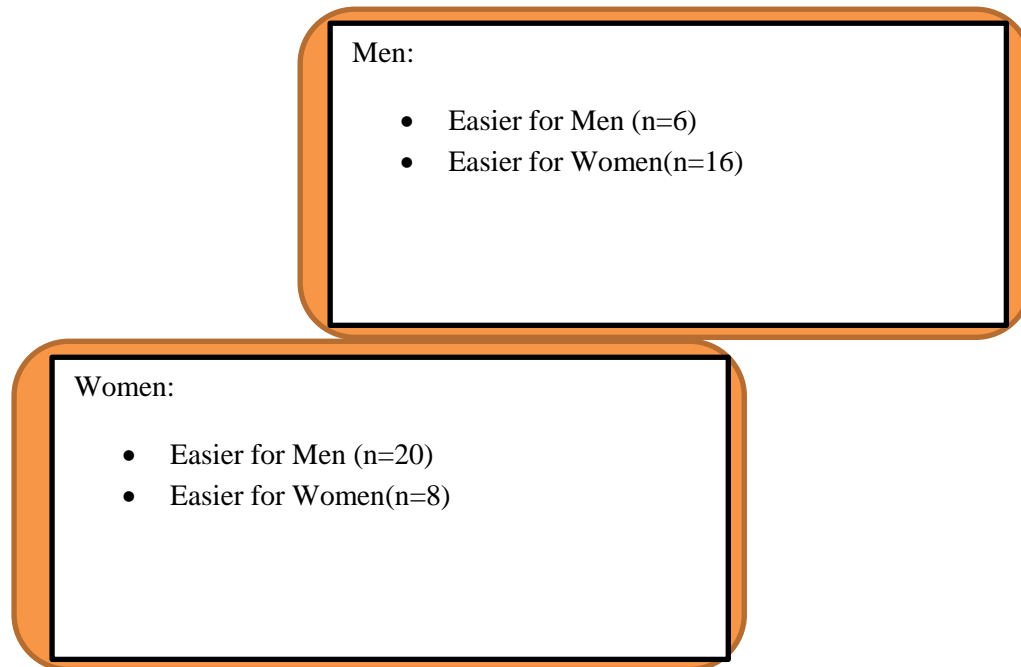


Figure 26 shows different views of participants on Gender Roles at this stage. When question was asked to the participants if gender in any way played a role in this setting and what were their views about for who was this stage of life easier, for a man or a woman?

When asked to the men, majority (16) men said that for women it was much easier as they just have to handle the house chores, gets everything asked for, do not have any financial responsibility. It is difficult for men as they have financial duties and responsibilities. Unlike females they do not let out their emotions every time they are overwhelmed, they keep everything to themselves. Whereas there were 6 men according to whom men lived an easier lifestyle at this stage of life as comparatively they had fewer responsibilities and could step out of the house anytime they wanted unlike women.

When the same question was asked to women, majority of 20 of them said that for men it is much easier as they only have financial duties to fulfill whereas women on the other

hand have household and societal challenges. Also they had to maintain and balance out many relationships. While frustrated, overwhelmed they could not step out of the house every time as men to distract themselves. Women tend to keep everything with themselves doesn't let it out. Whenever children are in any problem they always come to the mother because she is held responsible for them and their behavior. There were few women according to whom this stage of life was easier for women and not men as the men are the bread earner of the family, all financial responsibility are on them and unlike women they do not let out their emotions every time they are overwhelmed, they keep everything to themselves.

## Summary of Findings

**Table 5**

*Gender wise Comparative Analysis*

	Men	Women
<b>Caregivers</b>	There were few respondents that showed exceptions, where men performed the role of caregivers and looked after their wives because the wife had a few minor health difficulties that made taking responsibility for herself and the household difficult.	Women were usually expected to look after their husbands in Indian culture.
<b>Level of Dependency</b>	Care receivers are less completely reliant on others for financial stability than carers. While the majority of care recipients were men, the majority of them were on retirement, while some were running their own businesses or working part-time. Hence, all men be it caregivers or care receiver were financially independent.	Several females claim that, there was not much familial encouragement or support for them to work; therefore they were now reliant on others.
<b>Typical day routine</b>	Gender roles were clearly obvious in this category as well, with the results indicating that men caregivers were mostly involved in house finances and completing their jobs. Few of them participate in family tasks.	Women, on the other hand, have never claimed being involved in household financial decisions. The primary aspects were cooking and maintenance of the house.
<b>Tasks by Caregiver for Care receiver</b>	Men caregivers primarily took care of their partners in terms of financial decisions, purchasing	Women participants were found to take care of their spouses in terms of cleaning and house upkeep,

---

	<p>necessary items, hospital visits, transportation, and attending social functions, there were exceptions where men participants did household chores such as cooking, washing utensils and clothes, cleaning, and house maintenance because of their wife's physical health and these exceptions were only found in the dyads who were living all by themselves.</p>	<p>cooking, meal planning, medicine administration, hospital visits, and grooming.</p>
<b>Impact of caregiving</b>	<p>Men majorly had no impact of caregiving in any domain.</p>	<p>The majority of carers were women, they indicated some emotional and physical effects of caring for others. They had previously felt overwhelmed and physically fatigued as a result of the caregiving process.</p>
<b>Challenges</b>	<p>Men frequently struggled to cope with women's mood swings and conduct.</p>	<p>Women rarely suffer challenges, with the exception of mental breakdowns or physical exhaustion.</p>
<b>Expectations</b>	<p>Men often do not have high expectations of their caretakers, and they like to avoid interfering with their families and to allow everyone their own space.</p>	<p>Women continued to have certain expectations from their carers. One of the most prevalent is spending time with them. Other than that, they say, there are no expectations because it is both of our responsibilities to look after each other, and our requirements and needs are well recognized.</p>

---

**Table 6***Dyads living with and without Family wise Comparative Analysis*

	<b>Dyads living with family</b>	<b>Dyads living all by themselves</b>
<b>Caregivers</b>	The dyads living with family had other carers in addition to the primary caregiver, who were family members.	The dyads who lived alone either had no one to care for them other than their own spouse or had neighbors, relatives, children living nearby, or friends who looked for them.
<b>No. of hours spent</b>	Participants who lived with their children/family spent comparatively less time with their spouse than the dyad who lived alone (without family), since time was allocated among the other members of the dyad. The male participants used to spend their time with their grandchildren, leisure time with friends or handling their work.	The majority of participants were retired dyads who spent the majority of their time together, assisting each other with home responsibilities, dining together, socializing, and so on. While other participants were still working, they would contribute to their employment for a few hours or half of the day while spending the rest of the time with their spouse. Out of 25 caregivers 6 (all men) and out of 25 care receivers, 7 (all men) of them were still employed or engaged in work related activities.
<b>Thoughts about future</b>	Dyads who lived with relatives indicated concern over their children's settling and voiced a want to see their grandkids. Because they had children to care for, these dyads were less concerned about their spouse's well-being after death.	Dyads living alone had no other dreads than that their spouses would be alone if they died before.
<b>Challenges</b>	Dyads in this area encountered less issues like physical challenges since they had extra carers in the house to take after the care	Dyads in this area didn't say much about their difficulties, but they did say that certain things would be considerably better if their children lived



	<p>receiver whenever needed, mostly in the caregiver's absence.</p>	<p>with them. They were pleased with the way they were living. They did, however, indicate a desire to see their children more frequently.</p>
<b>Importance of caregiving</b>	<p>When questioned about the significance of caring, the majority of these dyads said that nothing is more essential than taking care of their spouse, since he or she is my husband or wife, and what else could be more important?</p>	<p>The participants majorly expressed their feeling by saying, if I won't take care of him/ her who else will?</p>
<b>Satisfaction with life</b>	<p>The majority of individuals were totally satisfied with their life. Although a handful of them expressed dissatisfaction with making some bad/unwanted decisions in the past (example career, disrespecting parent's decision)</p>	<p>The majority of individuals were entirely satisfied with their life. Although a few of them expressed disappointment with living life alone at this age, they wanted their children to be with them, and the couples who did not have children desired children.</p>
<b>Views on topics as whole</b>	<p>Dyads here showed less negative views on the elderly people in today's world. The majority of them have a nice life, living with their families. Few of them stated that the way children are raised, watching their parents take care of their elders, has taught them the same, and as a result, we are able to have the fruits of it. Despite this, several of them expressed sadness at seeing people their age living alone and struggling to make ends meet. Few were additionally concerned by how the generation is changing and how the love and respect for</p>	<p>The dyads living by themselves felt that priorities of younger people are now changing. Before, the interests of the family usually take priority over those of individual. But now it's the opposite. There is a decline in love and respect for elders</p> <p>5 dyads (3 living alone and 2 living with family) believed that living in vrudh aashram was beneficial since it provided all amenities and kept them out of the chaos.</p>

<b>Advice for older people</b>	<p>older people is fading day by day.</p> <p>Dyads living with family shared one piece of advice: all elderly people, at this time in their lives, should live with their families in order to be happy.</p>	<p>None of the dyads here advised living in joint families. Despite the fact that they always want their children to stay with them. Common advise was to not place too many expectations on others, to be happy with your current situation, and to become less involved in your family.</p>
<b>Stereotypical role distribution</b>	<p>Dyads living with family had more stereotypical role distribution as there were other members in the house to handle things, so the men of the house never entered kitchen for cooking or was never concerned for the maintenance of the house when maid was on leave, because he knew that his wife will take care along with his daughter in law(s)</p>	<p>Dyads living without family had comparatively less stereotypical role distribution, as there were only 2 people in the house who were looking after each other without any other major support, second reason being the male participants were majorly on their retirement. So the entire day they used to spend at home which led them to help their wives in household chores and maintaining the house.</p>

---

## **Discussion and Conclusion**

The world is changing in many ways for older persons with both positive and not so positive changes affecting their lives. This chapter attempts to explain the finding of the study in emerging socio-cultural context.

### **Structural, Functional and Cultural Changes**

#### ***Migration and Distant Care***

Migration, whether domestic or international, tends to increase the number of nuclear family units, leaving elder family members behind. The pattern is so widespread in some areas of India that shorthand for it has emerged: PICA, or Parents in India, Children Abroad (Prince et al 2007; Prince & Trebilco, Draper et al, 2005). The study found that maximum numbers of dyads were living by themselves without any major or primary support other than their spouse because few had no children others who had, their children migrated to different city or overseas due to better career options and settling down . The responsibilities of women have also evolved and because many of them are now employed full-time, they are less available to provide care to the elderly. Despite encouraging children for moving out for better future opportunities, older people prefer to live back home. In circumstances when children are not living with their elderly parents but are attempting to retain strong links and making attempts to provide care and support, even if they are separated by great distances, distance care is one such newer method of caring that has recently arisen (Kaushik, 2020). The study has found that, some of the participants though away from their families received distant care in form of

- Making sure to contact them once in a day
- Visit them once in a year or two
- Asking relatives or others to keep a check on them

- Inviting them at their place once in a year or two.

### *Changing Expectations of Older Persons*

Study findings talk about how the older persons occasionally expressed a desire for living alone or apart from their children or families. Some of them also reportedly felt like a burden to their children, which is why they chose to live away from them. Older persons expressed in different ways that they preferred to live alone for reasons such as need for personal independence, mutual space for self as well as children and longing to live life with dignity. These findings indicate a gradual change in expectations and caregiving preferences. Rights perspective emphasises that older people need their own space and independence. Disengagement theory also explains older people's desire to disengage from interfering in their children's lives as older people now may put more trust in younger generation's ability to take their own decisions and manage their own lives. At the same time they wish to avoid conflicts by ensuring clear boundaries. By disengaging at certain levels though, they become more engaged with their own lives which eventually be helpful for them, as well as societal value systems that now increasingly focus on individual rights and freedom explain the fact that older people did not want to meddle much in family affairs.

Some older persons were found to be caught up between rational thoughts about needs of present generation but still having expectations and disappointment at a subtle level about changed value system. There were dissatisfactions about their children not looking after them the way they looked after their own parents. These emotions and expectations create complex dynamics wherein younger generation may also be feeling pressured due to changes in society like increased cost of living, personal aspiration after higher education and exposure. Denser urban living, greater living expenses, and more consumerism are all contributing factors that make many families less likely to support the social, economic and psychological requirements of their older parents (Patel and Prince, 2001).

### **Role/Support of Daughters in Caregiving**

Every research of kinship networks in old age has shown a bias in favour of female-linked networks. Every aspect of parent-child interactions may be said to have this quality. Compared to males, women often reside closer to their families of origin and spend more time with their extended relatives. According to the findings of the present study, daughters were crucial support systems in providing emotional care in particular and providing the elderly persons with the care and attention they desired even when they lived with their sons. Participants claimed that they had a unique type of closeness with their daughters that could never be achieved with a son. According to Troll et al. (1979) when it becomes impossible for them to live alone, elder women are more likely than older males to move in with their children, and these children are often daughters rather than sons. This was seen in the study as there were two mothers who preferred to live with their daughters despite having sons. On the other hand, the study also found that despite stronger emotional care from daughters, there was a social taboo in living with a married daughter in her house and people preferred spending more time on a regular basis; however, living with them was perceived as less favourable.

### **Ageism**

The study found out the different contributions the elderly make in society and in the family, by being the caregiver to the other older persons as well as other family members by playing a supportive role in the household as well as grand parenting. With the increasing trend of dual earning couples, grandparents play a role as caregivers too. It is important that families and societies acknowledge and value contributions of older persons rather than considering them as a dependent population who are a burden on families, economies and societies.

## **Informal and Formal Caregiving**

The family is traditionally responsible for caring for the elderly in India (Panigrahi & Syamala, 2012). As per the social and cultural norms in India, It is a natural expectation and Kartavya of children/spouse to take care of their parents/other partner and provide them Seva at their old age. In fact, it is also believed that, a child/ spouse takes it as a blessing from god or an accumulation of good karma that they get an opportunity to take care of their parents/ other partner. In the same way the study shows how son and daughters being the caregivers even when their older parents were ageing. In other cases supportive role played by children in multigenerational families which gives sense of security to the older persons. Also the study found out that in the absence of main caregiver there were other informal support systems available which acted as protective factors for older people.

However due to societal transformation, the family, friends, and other support systems for the elderly are increasingly shrinking and older people may be are ill-prepared to deal with illness and incapacity on their own especially during incidences of temporary disabilities due to accidents, illnesses or terminal illness. The idea of alternate arrangements for the care of the elderly through institutional support has emerged as a result of these occurrences. The present study also found that, some families had availed home based services of full time/ part time nurses or physiotherapists in cases of health issues/ accidents/ falls and short spans of temporary disability. It is noteworthy that the participants belonged to upper middle and upper socioeconomic status and as a result had sufficient means to avail paid help and formal caregiving facilities which helped in avoiding additional challenges that families would encounter.

It was reported that, some of the participants were highly reliant on domestic helpers and assistive care carers for cooking, housekeeping, medication administration, and other tasks.

Observing the increase in reliance on formal caregivers for physical needs, should serve as a wake-up call for the government to establish various agencies/organizations where people who play the role of formal caregivers to the elderly are trained sufficiently to effectively care for them in various domains.

### **Implications of the Study**

The findings of the study has important implications

- It highlights and justifies the need for various organizations and agencies to train the formal care staff to care for older persons for range of care needs.
- It identifies the important qualities of caregivers as identified by care givers and care receivers which can be used for training the caregivers.
- Create awareness about contributions of older persons to fight ageism.
- Better community level living arrangements for older people living alone as well as provisions for safety and security of the older persons.

### **Limitations**

- Because of the Snowballing sampling approach, the researcher was able to obtain only dyads from the high and upper middle classes.
- At times it was difficult to make the participants talk or to get answers of certain questions even after probing.

## **Future Recommendations**

### ***For Future Research***

- The present study only included participants from upper and upper middle classes. It would be helpful to focus on experiences, issues and challenges of older adults from different the lower socioeconomic background as the findings are likely to be very different and will help in understanding the impact of the changing society across different contexts.
- The present research majorly included young old (60-74 years) participants. Future research should look at the caring arrangements of the oldest old (85-99 years) population as their characteristic and needs vary a lot and will help to throw light on issues and needs of oldest old care givers and receivers.

### ***For Policy makers***

- Policies and programmes for older persons must focus on preventing disability and dependency and promoting healthy ageing to ensure autonomy and independence among older persons for a long span of time to reap the benefits of increased life expectancy and the changes in care giving.
- Development of community living arrangements for older persons to allow opportunities to older persons for independent living with adequate support and opportunities of interaction with like-minded people.
  - Availability of trained and verified formal care including assistive home based carers, nurses, therapists and other professionals,
  - Accessibility to quality technological support and other support services for effective distant care.



### ***For Society in general***

- Societal changes are needed for gender sensitivity and gender bias free socialisation and roles to prepare both genders for all sorts of tasks including financial independence as well as caregiving as the implications of these are life-long.
- Society in general needs to appreciate the contributions of older persons towards the family and society at large and break free from negative prejudices about older persons as dependent and burden
- It will be helpful to help older persons to understand and appreciate the socio-cultural changes and the demands that it places on younger generation and for younger generation to develop the sensitivity and appreciation for older persons, and thus have health intergenerational bonding.

### **Conclusion**

The study represents the transition in traditional ideas of ageing. It also provides a subjective perspective on influences of modernization, urbanization and technological advancement on lifestyles and family structures. The findings also represent changing caregiving patterns of the older adults. It also represents the traditional beliefs of older adults against the modern society, but on the other hand the study reveals that the older adults are now changing their perceptions and understands the new generation.

Improved health care facilities and technological advancements is extending life expectancy however migration and urbanization have created dearth of younger caregivers. Due to this more and more older people are living alone or by themselves and assuming the role of caregivers for their partners, siblings, oldest old parents and in many cases grandchildren. Good health and physical functioning, sound socioeconomic conditions and availability of assistive and formal care on demand were found to be the important factors for

older caregivers and receivers. These findings point out at a need for some important actions and interventions including

- Focus on importance of healthy ageing to ensure autonomy and independence among older persons for a long span of time,
- Better Community living facilities for older couples or other dyads of older care givers and receivers,
- Availability of trained and verified formal care including assistive home based carers, nurses, therapists and other professionals,
- Better ways, quality and accessibility to technological support for effective distant care,
- Societal changes for gender sensitivity to prepare both genders for all sorts of tasks including financial independence as well as caregiving.

## References

- Arokiasamy, P., Bloom, D., Lee, J., Feeney, K., & Ozolins, M. (2011). Longitudinal aging study in India: vision, design, implementation, and some early results. *Progr Glob Demogr Aging*, 1-44. <https://core.ac.uk/download/pdf/6653625.pdf>
- Asis, M. M. B., Domingo, L., Knodel, J., & Mehta, K. (1995). Living arrangements in four Asian countries: A comparative perspective. *Journal of Cross-Cultural Gerontology*, 10, 145-162.  
<https://www.academia.edu/download/75322031/bf0097203420211128-28870-d8mvhv.pdf>
- Barusch, A. S., & Spaid, W. M. (1989). Gender differences in caregiving: why do wives report greater burden?. *The Gerontologist*, 29(5), 667-676.  
<https://academic.oup.com/gerontologist/article-abstract/29/5/667/660385>
- Barusch, A. S. (1988). Problems and coping strategies of elderly spouse caregivers. *The Gerontologist*, 28(5), 677-685. <https://academic.oup.com/gerontologist/article-abstract/28/5/677/630971>
- Bonsang, E. (2009). Does informal care from children to their elderly parents substitute for formal care in Europe?. *Journal of health economics*, 28(1), 143-154.  
<https://www.sciencedirect.com/science/article/pii/S0167629608001252>
- Brijnath, B. (2012). Why does institutionalised care not appeal to Indian families? Legislative and social answers from urban India. *Ageing & Society*, 32(4), 697-717.  
<https://www.cambridge.org/core/journals/ageing-and-society/article/why-does-institutionalised-care-not-appeal-to-indian-families-legislative-and-social-answers-from-urban-india/FE206172AD810DA2525DFAFE293ED22C>

Djellal, F., & Gallouj, F. (2006). Innovation in care services for the elderly. *The Service Industries Journal*, 26(03), 303-327.

<https://www.tandfonline.com/doi/abs/10.1080/02642060600570943>

Fernández-Carro, C. (2016). Ageing at home, co-residence or institutionalisation? Preferred care and residential arrangements of older adults in Spain. *Ageing & Society*, 36(3), 586-612. <https://www.cambridge.org/core/journals/ageing-and-society/article/ageing-at-home-coresidence-or-institutionalisation-preferred-care-and-residential-arrangements-of-older-adults-in-spain/A6FBE42607572D9956CC20781D3C9ABB>

Gannon, B., & Davin, B. (2010). Use of formal and informal care services among older people in Ireland and France. *The European Journal of Health Economics*, 11, 499-511. <https://link.springer.com/article/10.1007/s10198-010-0247-1>

Greenwood, N., Pound, C., Brearley, S., & Smith, R. (2019). A qualitative study of older informal carers' experiences and perceptions of their caring role. *Maturitas*, 124, 1-7. <https://www.sciencedirect.com/science/article/pii/S0378512219300878>

He, W., Goodkind, D., & Kowal, P. R. (2016). *An aging world: 2015*. [https://www.researchgate.net/profile/Paul-Kowal/publication/299528572\\_An\\_Aging\\_World\\_2015/links/56fd4be108ae17c8efaa1132/An-Aging-World-2015.pdf](https://www.researchgate.net/profile/Paul-Kowal/publication/299528572_An_Aging_World_2015/links/56fd4be108ae17c8efaa1132/An-Aging-World-2015.pdf)

Horowitz, A. (1985). Sons and daughters as caregivers to older parents: Differences in role performance and consequences. *The Gerontologist*, 25(6), 612-617. <https://academic.oup.com/gerontologist/article-abstract/25/6/612/580759>

Ingle, G. K., & Nath, A. (2008). Geriatric health in India: Concerns and solutions. *Indian journal of community medicine: official publication of Indian Association of*

*Preventive & Social Medicine*, 33(4), 214.

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2763704/>

Cho, T. Nakagawa, P. Martin, Y. Gondo, L. W. Poon & N. Hirose (2018): Caregiving centenarians: Cross-national comparison in Caregiver-Burden between the United States and Japan, *Aging & Mental Health*, DOI: 10.1080/13607863.2018.1544221 <https://doi.org/10.1080/13607863.2018.1544221>

Kaushik, A. (2020). Elder care from a distance: Emerging trends and challenges in the contemporary India. *Ageing issues and responses in India*, 97-113.

[https://link.springer.com/chapter/10.1007/978-981-15-5187-1\\_6](https://link.springer.com/chapter/10.1007/978-981-15-5187-1_6)

Kalwij, A., Pasini, G., & Wu, M. (2014). Home care for the elderly: the role of relatives, friends and neighbors. *Review of Economics of the Household*, 12(2), 379-404.

<https://link.springer.com/article/10.1007/s11150-012-9159-4>

Khaw, K. T. (1997). Healthy aging. *Bmj*, 315(7115), 1090-1096.

<https://www.bmj.com/content/315/7115/1090.short>

Kyuho Lee, Peter Martin & Leonard W. Poon (2017) Predictors of caregiving burden: impact of subjective health, negative affect, and loneliness of octogenarians and centenarians, *Aging & Mental Health*, 21:11, 1214-1221, DOI: 10.1080/13607863.2016.1206512

<http://dx.doi.org/10.1080/13607863.2016.1206512>

Laidlaw, K., Wang, D., Coelho, C., & Power, M. (2010). Attitudes to ageing and expectations for filial piety across Chinese and British cultures: A pilot exploratory evaluation. *Aging & Mental Health*, 14(3), 283-292.

<https://www.tandfonline.com/doi/abs/10.1080/13607860903483060>

Lamptey, I., Boateng, A., Hamenoo, E., & Agyemang, F. A. (2018). Exploring the experiences of elderly persons cared for by family caregivers in Ghana. *Int j innov res adv stud*, 5, 199-208. [http://www.ijiras.com/2018/Vol\\_5-Issue\\_6/paper\\_36.pdf](http://www.ijiras.com/2018/Vol_5-Issue_6/paper_36.pdf)

- Menezes, S., & Thomas, T. M. (2018). Status of the elderly and emergence of old age homes in India. *International Journal of Social Sciences and Management*, 5(1), 1-4.  
<https://www.nepjol.info/index.php/IJSSM/article/view/18972>
- Miller, B., & Cafasso, L. (1992). Gender differences in caregiving: fact or artifact?. *The gerontologist*, 32(4), 498-507. <https://academic.oup.com/gerontologist/article-abstract/32/4/498/601077>
- Panigrahi, A. K., & Syamala, T. S. (2012). *Living arrangement preferences and health of the institutionalised elderly in Odisha*. Institute for Social and Economic Change, 978-81-7791-147-3  
<http://isec.ac.in/WP%20291%20%20Akshay%20Kumar%20Panigrahi.pdf>
- Sonn, U., & Asberg, K. H. (1991). Assessment of activities of daily living in the elderly. A study of a population of 76-year-olds in Gothenburg, Sweden. *Journal of Rehabilitation Medicine*, 23(4), 193-202.  
<https://medicaljournalssweden.se/jrm/article/view/4191>
- Ugargol, A. P., & Bailey, A. (2018). Family caregiving for older adults: gendered roles and caregiver burden in emigrant households of Kerala, India. *Asian Population Studies*, 14(2), 194-210.  
<https://www.tandfonline.com/doi/abs/10.1080/17441730.2017.1412593>
- Velkoff, V. A. (2001). *Living arrangements and well-being of the older population: Future research directions*. New York, NY: United Nations, Department of Economic and Social Affairs, Population Division.  
[https://www.un.org/development/desa/pd/sites/www.un.org.development.desa.pd/files/unpd\\_egm\\_200002\\_velkoff.pdf](https://www.un.org/development/desa/pd/sites/www.un.org.development.desa.pd/files/unpd_egm_200002_velkoff.pdf)

## **Appendices**

### **Appendix A**

#### **Consent Form**

I am Mariyah Kapadia, student of The Maharaja Sayajirao University of Baroda, Gujarat, currently pursuing Senior Masters in Child Development and Education for Sustainable Development from the Faculty of Family and Community Sciences from the Department of Human Development and Family Studies.

As a part of my M.Sc. Dissertation, I am conducting a research study on To the older persons by the older persons- Study of Changing Patterns of Care Giving to Older Adults by Older Adults within families in Vadodara.

The above study will us help in understanding the arrangements, patterns, experiences and challenges of the older care receivers as well as care givers. Understanding of the changes, challenges, strategies adopted by these families and the emerging need for services will help in providing recommendations for services and policy making to come up with sustainable solutions for the sort of care giving.

As part of the data collection for this research I will need to conduct interviews of the caregivers and receivers who are 60 years and above. The interview will involve questions on care giving patterns, health issues and activities of daily living, availability of support systems, challenges and strategies found to be helpful and effective. The questions will also include aspects of perceptions, values, and emotions of the interviewee. Due to the qualitative nature of the study, the interview will take about an hour or more or sometimes even multiple interviews in consultation and with consensus of the interviewees. The interviews will be audio recorded in order to avoid loss of any important information. I

would like to assure you that the information obtained will remain strictly confidential and will be used solely for academic purpose only and anonymity will be maintained in sharing of the information.

**Consent:**

I have read and understood the above details and have been explained about the study in detail. Keeping all the above points in mind, I willingly give my consent to participate in the study and allow the researcher to conduct the interviews as well as record the same.

**Name:**

**Age:**

**Address:**

**Signature:**



### सहमति पत्र:

मैं मरियाह कपाड़िया ,डिपार्टमेंट ऑफ़ ह्यूमन डेवलपमेंट एंड फ़ैमिली स्टडीज़, फैकल्टी ऑफ़ फैमिली एंड कम्युनिटी साइंस, ध महाराजा सयाजीराओ यूनिवर्सिटी ऑफ़ बड़ौदा . मेरे एम.एससी के एक भाग के रूप में। निबंध ,मैं वृद्ध व्यक्तियों द्वारा वृद्ध व्यक्तियों पर एक शोध अध्ययन आयोजित कर रहा हूँ -वड़ोदरा में परिवारों के भीतर वृद्ध वयस्कों द्वारा वृद्ध वयस्कों को देखभाल देने के बदलते पैटर्न का अध्ययन।

उपरोक्त अध्ययन से वृद्ध देखभाल प्राप्त करने वालों के साथ-साथ देखभाल करने वालों की व्यवस्थाओं ,पैटर्न ,अनुभवों और चुनौतियों को समझने में मदद मिलेगी। इन परिवारों द्वारा अपनाए गए परिवर्तनों ,चुनौतियों ,रणनीतियों और सेवाओं की उभरती जरूरतों को समझने से देखभाल देने के लिए स्थायी समाधान के साथ आने के लिए सेवाओं और नीति बनाने के लिए सिफारिशें प्रदान करने में मदद मिलेगी।

इस शोध के लिए डेटा संग्रह के हिस्से के रूप में मुझे देखभाल करने वालों और प्राप्त करने वालों के साक्षात्कार आयोजित करने की आवश्यकता होगी जो 60वर्ष और उससे अधिक हैं। साक्षात्कार में देखभाल देने के पैटर्न ,स्वास्थ्य संबंधी मुद्दों और दैनिक जीवन की गतिविधियों ,सहायक प्रणालियों की उपलब्धता ,चुनौतियों और सहायक और प्रभावी पाई जाने वाली रणनीतियों पर प्रश्न शामिल होंगे। प्रश्नों में साक्षात्कारकर्ता की धारणाओं ,मूल्यों और भावनाओं के पहलू भी शामिल होंगे। अध्ययन की गुणात्मक प्रकृति के कारण ,साक्षात्कार में लगभग एक घंटे या उससे अधिक या कभी-कभी

साक्षात्कारकर्ताओं के परामर्श से और साक्षात्कारकर्ताओं की सहमति से कई साक्षात्कार भी होंगे।

किसी भी महत्वपूर्ण जानकारी के नुकसान से बचने के लिए साक्षात्कार की ऑडियो रिकॉर्डिंग की जाएगी। मैं आपको आश्वस्त करना चाहता हूँ कि प्राप्त की गई जानकारी पूरी तरह से गोपनीय रहेगी और इसका उपयोग केवल शैक्षणिक उद्देश्य के लिए ही किया जाएगा और जानकारी साझा करने में गुमनामी बनाए रखी जाएगी।

अनुमति:

मैंने उपरोक्त विवरण को पढ़ और समझ लिया है और मुझे अध्ययन के बारे में विस्तार से बताया गया है। उपरोक्त सभी बिंदुओं को ध्यान में रखते हुए, मैं स्वेच्छा से अध्ययन में भाग लेने के लिए अपनी सहमति देता हूँ और शोधकर्ता को साक्षात्कार आयोजित करने के साथ-साथ उसे रिकॉर्ड करने की अनुमति देता हूँ।

नाम:

आयु:

पता:

हस्ताक्षर:

### સંમતિ ફોર્મ:

હું મારીયાહ કાપડિયા છું, ગુજરાતની મહારાજા સયાજીરાવ યુનિવર્સિટી ઓફ બરોડાની વિદ્યાર્થીની, હાલમાં હુમાન ડેવલપમેન્ટ એન્ડ ફેમિલી સ્ટુડીએસ અભ્યાસ વિભાગમાંથી ફેકલ્ટી ઓફ ફેમિલી એન્ડ કોમ્યુનિટી સાયન્સમાંથી ટકાઉ વિકાસ માટે બાળ વિકાસ અને શિક્ષણમાં સિનિયર માસ્ટર્સ કરી રહી છું.

મારા M.Sc ના ભાગ રૂપે. નિબંધ, હું વૃદ્ધ વ્યક્તિઓ દ્વારા વૃદ્ધ વ્યક્તિઓ પર એક સંશોધન અભ્યાસ હાથ ધરું છું - વડોદરામાં પરિવારોમાં વૃદ્ધ પુખ્ત વયના લોકો દ્વારા વૃદ્ધ વયસ્કોને સંભાળ આપવાની બદલાતી પેટર્નનો અભ્યાસ.

ઉપરોક્ત અભ્યાસ અમને વૃદ્ધ સંભાળ મેળવનારાઓ તેમજ સંભાળ આપનારાઓની વ્યવસ્થા, પેટર્ન, અનુભવો અને પડકારોને સમજવામાં મદદ કરશે. આ પરિવારો દ્વારા અપનાવવામાં આવેલા ફેરફારો, પડકારો, વ્યૂહરચનાઓની સમજ અને સેવાઓની ઉભરતી જરૂરિયાત સેવાઓ માટે ભલામણો પૂરી પાડવામાં મદદ કરશે અને કાળજી આપવાના પ્રકાર માટે ટકાઉ ઉકેલો લાવવા માટે નીતિ ઘડવામાં મદદ કરશે.

આ સંશોધન માટેના ડેટા એકત્રીકરણના ભાગરૂપે મારે 60 વર્ષ અને તેથી વધુ ઉંમરના કેરગીવર્સ અને રીસીવર્સનો ઇન્ટરવ્યુ લેવાની જરૂર પડશે. ઇન્ટરવ્યુમાં સંભાળ આપવાની પેટર્ન,

આરોગ્ય સમસ્યાઓ અને રોજિંદા જીવનની પ્રવૃત્તિઓ, સહાયક પ્રણાલીઓની ઉપલબ્ધતા, પડકારો અને વ્યૂહરચનાઓ મદદરૂપ અને અસરકારક હોવાનું જાણવામાં આવશે. પ્રશ્નોમાં ઇન્ટરવ્યુ લેનારની ધારણાઓ, મૂલ્યો અને લાગણીઓના પાસાઓનો પણ સમાવેશ થશે. અભ્યાસના ગુણાત્મક સ્વભાવને લીધે, ઇન્ટરવ્યુમાં લગભગ એક કલાક કે તેથી વધુ સમય લાગશે અથવા કેટલીકવાર પરામર્શમાં અને ઇન્ટરવ્યુ લેનારાઓની સર્વસંમતિ સાથે બહુવિધ ઇન્ટરવ્યુ પણ લેવામાં આવશે. કોઈપણ મહત્વપૂર્ણ માહિતીની ખોટ ટાળવા માટે ઇન્ટરવ્યુ ઓડિયો રેકોર્ડ કરવામાં આવશે. હું તમને ખાતરી આપવા માંગુ છું કે પ્રાપ્ત માહિતી સખત રીતે ગોપનીય રહેશે અને તેનો ઉપયોગ ફક્ત શૈક્ષણિક હેતુ માટે જ કરવામાં આવશે અને માહિતીની વહેંચણીમાં અનામી જાળવવામાં આવશે.

સંમતિ:

મેં ઉપરોક્ત વિગતો વાંચી અને સમજી લીધી છે અને અભ્યાસ વિશે વિગતવાર સમજાવવામાં આવ્યું છે. ઉપરોક્ત તમામ મુદ્દાઓને ધ્યાનમાં રાખીને, હું સ્વેચ્છાએ અભ્યાસમાં ભાગ લેવા માટે મારી સંમતિ આપું છું અને સંશોધકને ઇન્ટરવ્યુ લેવા તેમજ રેકોર્ડ કરવાની મંજૂરી આપું છું.

નામ:

ઉંમર:

સરનામું:

હસ્તાક્ષર:

## APPENDIX B

### Interview Schedule

#### BACKGROUND INFORMATION:

- Name
- Age
- Sex
- Marital Status
- Number of Children
- Living arrangement
  - Own house
  - Own flat
  - Rented house
  - Rented flat
- Living with:
  - Alone
  - With spouse
  - With spouse and child
  - Others
- Level of Education
  - 10<sup>th</sup> pass
  - 12<sup>th</sup> pass
  - Graduated
  - Post Graduated
  - Others
- Self- perception about health
  - Very good
  - Good
  - Average
  - Poor
  - Very poor (optional)
- Health issues
- Regular medication
- Years of suffering from any disease (s)
- Income
- Occupation
  - Present
  - Past

- Sources of income
- Family members

Relationship	Age	Marital status	Where do they live

- Any paid help?
  - Domestic work
  - Cook
  - Carer
  - Nurse
  - Any other
- If yes: (Carers)
  - Their age,
  - Qualification
  - Source
  - Tasks they perform
- Care routine: a typical day (describe a typical routine day)

As a primary caregiver, what are the different tasks you do you do for the older family member? What does the care giving look like- what are the tasks where you assist the person?

Tasks	Daily	Weekly	Monthly	SOS
1. Cleaning and house maintenance				
2. Cooking/ meal planning/ care about proper nutrition/ Feeding				
3. Administering medications				
4. Hospital appointments/ health visits to doctors				
5. Instances of hospitalization				
6. Personal care (Bath, toilet visits, grooming)				
7. Transportation				
8. Mobility support				
9. Social obligations/ Social interactions				
10. Financial management				
11. Others (Specify)				

- What are the numbers of hour you spend with them (care recipients)? On daily basis

Tasks	Daily	Weekly	Monthly	SOS
1. Cleaning and house maintenance				
2. Cooking/ meal planning/ care about proper nutrition/ Feeding				
3. Administering medications				
4. Hospital appointments/ health visits to doctors				
5. Instances of hospitalization				
6. Personal care (Bath, toilet visits, grooming)				
7. Transportation				
8. Mobility support				
9. Social obligations/ Social interactions				
10. Financial management				
11. Others (Specify)				

**Availability of support:**

1. When you are unavailable in case of any emergency or any prior commitments, who takes care/responsibility of the care recipient? In which areas is help more required?
2. Who else helps in care giving? What are the things that they do? Do you have any support?
3. You being the primary caregiver, who takes your responsibility and take care of you?
4. Who takes care of the finance? Do you have any health insurance or any insurance?

**Caregivers:**

**Views/Attitude/Experiences:**

1. How do you feel about being a primary care taker at this age?
2. What qualities are very important to take up the responsibility of care giving?
3. How important is it for you to play this role and why?
4. What makes it challenging? As a primary caregiver, what do you feel is the most difficult part of caregiving? What makes it manageable?
5. What motivates you to keep going? (Probe with whys to understand in depth)
6. Given a choice would you like the living and care giving arrangements to be any different and what would that be?
7. What would be your advice for older people (older couples or two generation of older adults) are living by themselves?
8. Do you think, gender in any way plays a role in this setting? Example;
  - What are the additional challenges that you as a woman/man carer had to face?
  - Are there any advantages women/men as care giver gets?

- Is it more difficult for men or women? Which tasks in particular are more challenging?
- How can your life as an older carer be made better?

### **Impact:**

1. Does this role of care taking have any impact on you? (physically, emotionally, socially, financially)
2. Is there any impact on your physical and mental health? If yes, then please elaborate.
3. Is there any impact that you consider as positive?
4. Is there any impact that you consider negative?
5. Has your relationship with your care recipient change over time? If yes, then how?
6. Does it ever affect you emotionally? If yes,
  - How
  - Coping strategies
7. What are your thoughts about future?

### **Challenges and Rewards:**

1. With all the responsibilities of the caregiving, how do you manage your personal and social life? (hobbies, interests, career, business, relationships)
2. Are there any practical issues you face or any challenging times? (challenges with travelling, cooking, bathing) If yes, how do you deal with those?
3. All your life, you must have played different roles, do you see them changing over time? If yes, how do you feel about these changes?
4. Were there any particular challenges you faced, during Covid-19?
5. Along with challenges do you think there are also some rewards of caregiving? (Example: sense of gratitude)

### **Self-care and Coping:**

1. What do you do for your self-care? (Physical, emotional and mental care)
2. Along with self-care, you must have any hobby or things you like to do? If yes, can you pursue those?
3. How do you take care of your mental health/emotional wellbeing/ peace? Coping strategies.
4. What factors (People/ activities/ beliefs) help in meeting the demands of care giving?

### **Views on the topic as a whole:**

1. What are your views on care of older persons in today's time in India?
2. Is this something different from what always used to happen in our Indian society or is this something new? If yes, what is changing, how?



- How can things be made better for older persons who are care givers?

### Care recipients:

- Are you able to do these activities on your own without help? If not, what help is needed?

Activities	Independently	Need Assistance	Dependent
Bathe			
Getting dressed			
Going out			
Toilet			
Transfer out of bed			
Controlling urine			
Feed yourself			
Brushing teeth			
Laundry			
Taking medications			
Managing money			
Others			

- Who is the primary caregiver?

### Expectations:

- What are your expectations from your caregiver?
- In your view what can someone do to / what qualities and skills one must have to qualify as a good care giver?
- If you could change something about your care giver, what would that be?

### Impact:

- Has your relationship with your caregiver changed over time? If yes, then how?
- Can you spend one entire day without your caregiver? If yes, how does it feel like? Is there any other caregiver? If yes, who are they and what all the do?
- What are your thoughts about future?

### **Views and Attitude:**

1. What are your views on care of older persons in today's time in India?
2. Is this something different from what always used to happen in our Indian society or is this something new? If yes, what is changing, how?
3. How can things be made better for older persons who need care giver support?
4. What is the best care arrangement for the older family members according to you? Why?
5. On a scale of 1-10 where 1 is least and 10 is the most, how much are you satisfied with the care you receive?
6. Given a choice would you like the arrangements to be any different and what would that be? If yes, what would that be?
7. What would be your advice for older people (older couples or two generation of older adults) who are living by themselves?
8. Do you think, gender in any way plays a role in this setting OR With all the challenges one faces at this stage, for whom do you think it's more difficult, a man or a woman? Example;
  - What are the additional challenges that you as a woman/man carer had to face?
  - Are there any advantages women/men as care giver gets?
  - Is it more difficult for men or women? Which tasks in particular are more challenging?
  - How can your life as an older person be made better?
9. Who takes care of the finance? What all arrangements have you made? Do you have any health insurance or any other?

### **Self-care and Coping:**

1. What do you do for your self-care? (Physical, emotional and mental care)
2. Along with self-care, you must have any hobby or things you like to do? If yes, can you pursue those?
3. What factors (People/ activities/ beliefs) help in meeting the demands of care giving

### **Challenges:**

1. What are some of the challenges that you face – in day to day living, emergencies, other occasions (health emergencies, visiting places, social life)
2. Are there any advantages or good things about being cared for by an older family member?
3. Were there any particular challenges you faced, during Covid-19?

❖ વ્યક્તિગત માહિતી:

· નામ

· ઉંમર

· સેક્સ

· વૈવાહિક સ્થિતિ

· બાળકોની સંખ્યા

• રહેવાની વ્યવસ્થા

○ પોતાનું ઘર

○ પોતાનો ફ્લેટ

○ ભાડાનું ઘર

○ ભાડે આપેલ ફ્લેટ

· કોના સાથે રહેવું:

○ એકલા

○ જીવનસાથી સાથે

○ જીવનસાથી અને બાળક સાથે

○ અન્ય

- શિક્ષણનું સ્તર

- 10મું પાસ
- 12મું પાસ
- સ્નાતક થયા
- અનુસ્નાતક
- અન્ય

- સ્વાસ્થ્ય વિશે સ્વ-દ્રષ્ટિ

- ખૂબ સારું
- સારું
- સરેરાશ
- ખરાબ
- ખૂબ જ ખરાબ (વૈકલ્પિક)

- આરોગ્ય મુદ્દાઓ

- નિયમિત દવા
- કોઈપણ રોગ (ઓ) થી પીડાતા વર્ષો
- આવક
  - વ્યવસાય
    - હાજ
    - ભૂતકાળ

- આવકના સ્ત્રોતો

· પરિવારના સદસ્યો

સંબંધ	ઉંમર	વૈવાહિક સ્થિતિ	તેઓ ક્યાં રહે છે

• કોઈ ચૂકવેલ મદદ?

- ☐ ઘરેલું કામ
- ☐ ફૂક
- ☐ સંભાળ રાખનાર
- ☐ નર્સ
- ☐ અન્ય કોઈપણ

· જો હા: (કેરસ)

- ☐ તેમની ઉંમર,
- ☐ લાયકાત
- ☐ સ્ત્રોત
- ☐ તેઓ જે કાર્યો કરે છે

- સંભાળ નિયમિત: એક સામાન્ય દિવસ (સામાન્ય નિયમિત દિવસનું વર્ણન કરો)

- પ્રાથમિક સંભાળ રાખનાર તરીકે, તમે કુટુંબના વૃદ્ધ સભ્ય માટે તમે કયા વિવિધ કાર્યો કરો છો? સંભાળ આપવી એ કેવું દેખાય છે- તમે વ્યક્તિને મદદ કરો છો તે કાર્યો કયા છે?

કાર્યો	દૈનિક	સાપ્તાહિક	માસિક	SOS
1. સફાઈ અને ઘરની જાળવણી				
2. રસોઈ / ભોજનનું આયોજન / યોગ્ય પોષણ / ખોરાક વિશે કાળજી				
3. દવાઓનું સંચાલન				
4. ડોક્ટરોની હોસ્પિટલ એપોઇન્ટમેન્ટ/આરોગ્ય મુલાકાત				
5. હોસ્પિટલમાં દાખલ થવાના ઉદાહરણો				
6. વ્યક્તિગત સંભાળ (સ્નાન, શૌચાલયની મુલાકાત, માવજત)				
7. પરિવહન				
8. ગતિશીલતા આધાર				
9. સામાજિક જવાબદારીઓ/સામાજિક ક્રિયાપ્રતિક્રિયાઓ				
10. નાણાકીય વ્યવસ્થાપન				
11. અન્ય (સ્પષ્ટ કરો)				

૦ તમે તેમની સાથે કેટલા કલાકો વિતાવો છો (કેર પ્રાપ્તકર્તાઓ) દૈનિક ધોરણે.

❖ આધારની ઉપલબ્ધતા:

1. જ્યારે તમે કોઈપણ કટોકટીના કિસ્સામાં અથવા કોઈપણ પૂર્વ પ્રતિબદ્ધતાના કિસ્સામાં અનુપલબ્ધ હોવ, ત્યારે સંભાળ પ્રાપ્તકર્તાની સંભાળ/જવાબદારી કોણ લે છે? કયા ક્ષેત્રોમાં મદદની વધુ જરૂર છે?
2. સંભાળ આપવામાં બીજું કોણ મદદ કરે છે? તેઓ જે વસ્તુઓ કરે છે તે શું છે? શું તમારી પાસે કોઈ આધાર છે?

કાર્યો	દૈનિક	સાપ્તાહિક	માસિક	SOS
1. સફાઈ અને ઘરની જાળવણી				
2. રસોઈ / ભોજનનું આયોજન / યોગ્ય પોષણ / ખોરાક વિશે કાળજી				
3. દવાઓનું સંચાલન				
4. ડોક્ટરોની હોસ્પિટલ એપોઇન્ટમેન્ટ/આરોગ્ય મુલાકાત				
5. હોસ્પિટલમાં દાખલ થવાના ઉદાહરણો				
6. વ્યક્તિગત સંભાળ (સ્નાન, શૌચાલયની મુલાકાત, માવજત)				
7. પરિવહન				
8. ગતિશીલતા આધાર				
9. સામાજિક જવાબદારીઓ/સામાજિક ક્રિયાપ્રતિક્રિયાઓ				
10. નાણાકીય				

વ્યવસ્થાપન				
11. અન્ય (સ્પષ્ટ કરો)				

3. તમે પ્રાથમિક સંભાળ રાખનાર છો, તમારી જવાબદારી કોણ લે છે અને તમારી સંભાળ રાખે છે?
4. નાણાંની સંભાળ કોણ રાખે છે? શું તમારી પાસે કોઈ સ્વાસ્થ્ય વીમો કે કોઈ વીમો છે?

❖ સંભાળ રાખનાર:

દૃશ્યો/વૈભવ/અનુભવો:

1. આ ઉંમરે પ્રાથમિક સંભાળ લેનાર બનવા વિશે તમને કેવું લાગે છે?
  2. સંભાળ આપવાની જવાબદારી ઉપાડવા માટે કયા ગુણો ખૂબ જ મહત્વપૂર્ણ છે?
  3. આ ભૂમિકા ભજવવી તમારા માટે કેટલું મહત્વનું છે અને શા માટે?
  4. શું તેને પડકારરૂપ બનાવે છે? પ્રાથમિક સંભાળ રાખનાર તરીકે, તમને શું લાગે છે કે સંભાળ રાખવાનો સૌથી મુશ્કેલ ભાગ શું છે? શું તેને વ્યવસ્થિત બનાવે છે?
  5. તમને આગળ વધવા માટે શું પ્રેરણા આપે છે? (ઉંડાણથી સમજવા માટે શા માટે તપાસ કરો)
  6. પસંદગી આપવામાં આવે તો શું તમે ઈચ્છો છો કે રહેવાની અને સંભાળ આપવાની વ્યવસ્થા કોઈ અલગ હોય અને તે શું હશે?
  7. વૃદ્ધ લોકો (વૃદ્ધ યુગલો અથવા વૃદ્ધ વયસ્કોની બે પેઢી) એકલા જીવી રહ્યા છે તે માટે તમારી સલાહ શું હશે?
  8. શું તમને લાગે છે કે આ સેટિંગમાં લિંગ કોઈ પણ રીતે ભૂમિકા ભજવે છે? ઉદાહરણ;
- એક મહિલા/પુરુષ સંભાળ રાખનાર તરીકે તમારે કયા વધારાના પડકારોનો સામનો કરવો પડ્યો હતો?
  - શું સંભાળ આપનાર તરીકે સ્ત્રીઓ/પુરુષોને કોઈ લાભ મળે છે?



- શું તે પુરુષો કે સ્ત્રીઓ માટે વધુ મુશ્કેલ છે? ખાસ કરીને કયા કાર્યો વધુ પડકારરૂપ છે?
- વૃદ્ધ સંભાળ રાખનાર તરીકે તમારું જીવન કેવી રીતે બહેતર બનાવી શકાય?

અસર:

1. શું કાળજી લેવાની આ ભૂમિકા તમારા પર કોઈ અસર કરે છે? (શારીરિક, ભાવનાત્મક, સામાજિક, આર્થિક રીતે)
2. શું તમારા શારીરિક અને માનસિક સ્વાસ્થ્ય પર કોઈ અસર છે? જો હા, તો કૃપા કરીને વિગતવાર જણાવો.
3. શું એવી કોઈ અસર છે જેને તમે હકારાત્મક માનો છો?
4. શું એવી કોઈ અસર છે જેને તમે નકારાત્મક માનો છો?
5. શું સમય જતાં તમારા સંભાળ પ્રાપ્તકર્તા સાથેના તમારા સંબંધો બદલાય છે? જો હા, તો કેવી રીતે?
6. શું તે ક્યારેય તમને ભાવનાત્મક રીતે અસર કરે છે? જો હા,
- કેવી રીતે
- મુકાબલો વ્યૂહરચના
7. ભવિષ્ય વિશે તમારા વિચારો શું છે?

પડકારો અને પુરસ્કારો:

1. સંભાળની તમામ જવાબદારીઓ સાથે, તમે તમારા વ્યક્તિગત અને સામાજિક જીવનનું સંચાલન કેવી રીતે કરો છો? (શોખ, રુચિઓ, કારકિર્દી, વ્યવસાય, સંબંધો)
2. શું તમે કોઈ વ્યવહારિક સમસ્યાઓનો સામનો કરો છો અથવા કોઈ પડકારજનક સમય છે? (મુસાફરી, રસોઈ, સ્નાન સાથેના પડકારો) જો હા, તો તમે તેનો સામનો કેવી રીતે કરશો?
3. તમારી આખી જીંદગી, તમે જુદી જુદી ભૂમિકાઓ ભજવી હશે, શું તમે તેમને સમય સાથે બદલાતા જુઓ છો? જો હા, તો તમને આ ફેરફારો વિશે કેવું લાગે છે?
4. શું કોવિડ-19 દરમિયાન તમે કોઈ ખાસ પડકારોનો સામનો કર્યો હતો?

5. શું તમને લાગે છે કે પડકારો સાથે સંભાળ રાખવાના કેટલાક પુરસ્કારો પણ છે? (ઉદાહરણ: કૃતજ્ઞતાની ભાવના)

સ્વ-સંભાળ અને સામનો:

1. તમે તમારી સ્વ-સંભાળ માટે શું કરો છો? (શારીરિક, ભાવનાત્મક અને માનસિક સંભાળ)
2. સ્વ-સંભાળની સાથે, તમારે કોઈ શોખ અથવા વસ્તુઓ કરવી જોઈએ? જો હા, તો શું તમે તેનો પીછો કરી શકશો?
3. તમે તમારા માનસિક સ્વાસ્થ્ય/ભાવનાત્મક સુખાકારી/શાંતિની કેવી રીતે કાળજી લો છો? સામનો વ્યૂહરચના.
4. સંભાળ આપવાની માંગને પહોંચી વળવામાં કયા પરિબલો (લોકો/પ્રવૃત્તિઓ/માન્યતાઓ) મદદ કરે છે?

સમગ્ર વિષય પરના મંતવ્યો:

1. ભારતમાં આજના સમયમાં વૃદ્ધ વ્યક્તિઓની સંભાળ અંગે તમારા વિચારો શું છે?
2. શું આ આપણા ભારતીય સમાજમાં હંમેશા બનતું હતું તેનાથી કંઈક અલગ છે અથવા આ કંઈક નવું છે? જો હા, તો શું બદલાઈ રહ્યું છે, કેવી રીતે?
3. સંભાળ આપનાર વૃદ્ધ વ્યક્તિઓ માટે વસ્તુઓ કેવી રીતે વધુ સારી બનાવી શકાય

❖ સંભાળ પ્રાપ્તકર્તાઓ:

- 1) શું તમે મદદ વિના આ પ્રવૃત્તિઓ જાતે કરી શકશો? જો નહીં, તો કઈ મદદની જરૂર છે?

પ્રવૃત્તિઓ	સ્વતંત્ર રીતે	સહાયની જરૂર છે	આશ્રિત
સ્નાન કરો			
પોશાક પહેરવો			
બહાર જવું			
શૌચાલય			
પથારીની બહાર સ્થાનાંતરિત કરો			
પેશાબ પર નિયંત્રણ રાખવું			
તમારી જાતને ખવડાવો			
દાતાણ કરું છું			
લોન્ડ્રી			
દવાઓ લેવી			
પૈસાનું સંચાલન			
અન્ય			

## 2) પ્રાથમિક સંભાળ રાખનાર કોણ છે?

અપેક્ષાઓ:

1. તમારા સંભાળ રાખનાર પાસેથી તમારી શું અપેક્ષાઓ છે?
2. તમારા મતે કોઈ વ્યક્તિ શું કરી શકે છે / સારા સંભાળ આપનાર તરીકે લાયક બનવા માટે વ્યક્તિ પાસે કયા ગુણો અને કુશળતા હોવી જોઈએ?
3. જો તમે તમારા સંભાળ આપનાર વિશે કંઈક બદલી શકો છો, તો તે શું હશે?

અસર:

1. શું સમય જતાં તમારા સંભાળ રાખનાર સાથેના તમારા સંબંધો બદલાયા છે? જો હા, તો કેવી રીતે?
2. શું તમે તમારા સંભાળ રાખનાર વિના એક આખો દિવસ પસાર કરી શકો છો? જો હા, તો કેવું લાગે છે? શું અન્ય કોઈ સંભાળ રાખનાર છે? જો હા, તો તેઓ કોણ છે અને બધા શું કરે છે?

૩. ભવિષ્ય વિશે તમારા વિચારો શું છે?

મંતવ્યો અને વલણ:

૧. ભારતમાં આજના સમયમાં વૃદ્ધ વ્યક્તિઓની સંભાળ અંગે તમારા વિચારો શું છે?
૨. શું આ આપણા ભારતીય સમાજમાં હંમેશા બનતું હતું તેનાથી કંઈક અલગ છે અથવા આ કંઈક નવું છે? જો હા, તો શું બદલાઈ રહ્યું છે, કેવી રીતે?
૩. સંભાળ આપનાર સહાયની જરૂર હોય તેવા વૃદ્ધ વ્યક્તિઓ માટે વસ્તુઓ કેવી રીતે વધુ સારી બનાવી શકાય?
૪. તમારા મતે પરિવારના વૃદ્ધ સભ્યો માટે શ્રેષ્ઠ સંભાળની વ્યવસ્થા શું છે? શા માટે?
૫. ૧-૧૦ ના સ્કેલ પર જ્યાં ૧ સૌથી ઓછો છે અને ૧૦ સૌથી વધુ છે, તમે જે સંભાળ મેળવો છો તેનાથી તમે કેટલા સંતુષ્ટ છો? પસંદગી આપવામાં આવે તો શું તમે ઈચ્છો છો કે વ્યવસ્થાઓ કોઈ અલગ હોય અને તે શું હશે? જો હા, તો તે શું હશે?
૬. વયોવૃદ્ધ લોકો (વૃદ્ધ યુગલો અથવા બે પેઢીના વૃદ્ધો) કે જેઓ એકલા રહેતા હોય તેઓ માટે તમારી સલાહ શું હશે?
૭. શું તમને લાગે છે કે, આ સેટિંગમાં લિંગ કોઈ પણ રીતે ભૂમિકા ભજવે છે અથવા આ તબક્કે વ્યક્તિ જે પણ પડકારોનો સામનો કરે છે, તે કોના માટે વધુ મુશ્કેલ છે, પુરુષ કે સ્ત્રી? ઉદાહરણ;
  - એક મહિલા/પુરુષ સંભાળ રાખનાર તરીકે તમારે કયા વધારાના પડકારોનો સામનો કરવો પડ્યો હતો?
  - શું સંભાળ આપનાર તરીકે સ્ત્રીઓ/પુરુષોને કોઈ લાભ મળે છે?
  - શું તે પુરુષો કે સ્ત્રીઓ માટે વધુ મુશ્કેલ છે? ખાસ કરીને કયા કાર્યો વધુ પડકારરૂપ છે?
  - વૃદ્ધ વ્યક્તિ તરીકે તમારું જીવન કેવી રીતે બહેતર બનાવી શકાય?
૮. નાણાની સંભાળ કોણ રાખે છે? તમે શું બધી વ્યવસ્થા કરી છે? શું તમારી પાસે કોઈ સ્વાસ્થ્ય વીમો છે કે અન્ય કોઈ?

સ્વ-સંભાળ અને સામનો:

1. તમે તમારી સ્વ-સંભાળ માટે શું કરો છો? (શારીરિક, ભાવનાત્મક અને માનસિક સંભાળ)
2. સ્વ-સંભાળની સાથે, તમારે કોઈ શોખ અથવા વસ્તુઓ કરવી જોઈએ? જો હા, તો શું તમે તેનો પીછો કરી શકશો?
3. સંભાળ આપવાની માંગને પહોંચી વળવામાં કયા પરિબલો (લોકો/પ્રવૃત્તિઓ/માન્યતાઓ) મદદ કરે છે?

પડકારો:

1. તમે કયા પડકારોનો સામનો કરો છો - રોજિંદા જીવનમાં, કટોકટી, અન્ય પ્રસંગો (આરોગ્ય કટોકટી, સ્થળોની મુલાકાત, સામાજિક જીવન)
2. શું કુટુંબના વૃદ્ધ સભ્ય દ્વારા કાળજી લેવાના કોઈ ફાયદા અથવા સારી બાબતો છે?
3. શું કોવિડ-19 દરમિયાન તમે કોઈ ખાસ પડકારોનો સામનો કર્યો હતો?

### व्यक्तिगत जानकारी:

- नाम
- आयु
- लिंग
- वैवाहिक स्थिति
- बच्चों की संख्या

### रहने की व्यवस्था

- ओ खुद का घर
- ओ खुद का फ्लैट
- ओ किराए का घर
- ओ किराए का फ्लैट

### शिक्षा का स्तर

- 10वीं पास
- 12वीं पास
- स्नातक
- स्नातकोत्तर
- अन्य

### स्वास्थ्य की स्थिति

- बहुत अच्छा
- बढ़िया
- ठीक
- खराब
- बहुत खराब (वैकल्पिक)

### स्वास्थ्य के मुद्दों

- नियमित दवा
- किसी भी रोग से पीड़ित होने का वर्ष
- आय

### व्यवसाय

उपस्थित

विगत

• आमदनी का जरिया

• परिवार के सदस्य

रिश्ता	आयु	वैवाहिक स्थिति	वे कहाँ रहते हैं?

### • कोई सशुल्क सहायता?

- घरेलू काम
- कुक
- देखभालकर्ता
- नर्स
- कोई अन्य

• यदि हाँ: (देखभालकर्ता)

- उनकी उम्र,
- योग्यता
- स्रोत
- कार्य जो वे करते हैं

• देखभाल की दिनचर्या: एक सामान्य दिन

• जब हम कहते हैं कि आप प्राथमिक देखभालकर्ता हैं, तो आप देखभाल करने के लिए क्या करते हैं?

या

देखभाल करने वाला कैसा दिखता है- वे कौन से कार्य हैं जिनमें आप व्यक्ति की सहायता करते हैं?

- दैनिक आधार पर
- साप्ताहिक आधार
- मासिक आधार
- कार्य दैनिक साप्ताहिक मासिक एसओएस
  - सफाई और घर का रखरखाव
  - खाना बनाना/भोजन योजना/उचित पोषण/भोजन की देखभाल
  - दवा देना
  - अस्पताल में मुलाकात/चिकित्सकों के स्वास्थ्य दौरे
  - अस्पताल में भर्ती होने के उदाहरण
  - व्यक्तिगत देखभाल (स्नान, शौचालय का दौरा, संवारना)
  - परिवहन
  - गतिशीलता समर्थन
  - सामाजिक दायित्व / सामाजिक संपर्क
  - वित्तीय प्रबंधन
  - अन्य (निर्दिष्ट करें)

• आप उनके (देखभाल प्राप्तकर्ताओं) के साथ कितने घंटे बिताते हैं? दैनिक आधार पर।

समर्थन की उपलब्धता:

1. जब आप किसी आपात स्थिति या किसी पूर्व प्रतिबद्धता के मामले में अनुपलब्ध होते हैं, तो देखभाल प्राप्तकर्ता की देखभाल/जिम्मेदारी कौन लेता है?
2. देखभाल करने में और कौन मदद करता है? वे कौन सी चीजें हैं जो वे करते हैं? क्या आपके पास कोई समर्थन है?

- एक। रोज



- साप्ताहिक
- महीने के
- आप देखभालकर्ता होने के बारे में कैसा महसूस करते हैं?
- क्या आपको यह अपेक्षाकृत आसान और प्रबंधनीय या चुनौतीपूर्ण लगता है?

3. आप प्राथमिक देखभालकर्ता होने के नाते, आपकी जिम्मेदारी कौन लेता है और आपकी देखभाल करता है?

4. इस स्तर पर वित्तीय सुरक्षा महत्वपूर्ण है। वित्त की देखभाल कौन करता है? क्या आपके पास कोई स्वास्थ्य बीमा है?

### देखभाल करने वाले:

विचार और रवैया:

1. आप इस उम्र में प्राथमिक देखभालकर्ता होने के बारे में कैसा महसूस करते हैं?
2. इस जिम्मेदारी को उठाने के लिए कौन से गुण बहुत जरूरी हैं?
3. प्रभावी देखभाल प्रदान करने के लिए कौन से कौशल महत्वपूर्ण हैं?
4. यह भूमिका निभाना आपके लिए कितना महत्वपूर्ण है और क्यों?
5. क्या इसे चुनौतीपूर्ण बनाता है? एक प्राथमिक देखभालकर्ता के रूप में, आपको क्या लगता है कि देखभाल करने का सबसे कठिन हिस्सा क्या है? क्या इसे प्रबंधनीय बनाता है?
6. आपको चलते रहने के लिए क्या प्रेरित करता है? (क्यों के साथ गहराई से समझने के लिए जांच करें)
7. एक विकल्प दिए जाने पर क्या आप चाहते हैं कि व्यवस्था कुछ अलग हो और वह क्या होगा?
8. जब आप अन्य समकक्षों को अन्य समर्थन प्रणाली वाले देखते हैं तो आप कैसा महसूस करते हैं?
9. वृद्ध लोगों के लिए आपकी क्या सलाह होगी (बूढ़े जोड़े या वृद्ध वयस्कों की दो पीढ़ी) जो अकेले रह रहे हैं?
10. क्या आपको लगता है कि इस सेटिंग में लिंग किसी भी तरह से भूमिका निभाता है? उदाहरण;

- महिला देखभालकर्ताओं को किन अतिरिक्त चुनौतियों का सामना करना पड़ता है?
- क्या देखभालकर्ता के रूप में महिलाओं को कोई लाभ मिलता है?
- क्या यह पुरुषों या महिलाओं के लिए अधिक कठिन है? कौन सा रोल ज्यादा चैलेंजिंग है?
- वृद्ध देखभालकर्ताओं का जीवन कैसे बेहतर बनाया जा सकता है?

#### प्रभाव:

1. क्या देखभाल करने की इस भूमिका का आप पर कोई प्रभाव पड़ता है?
2. क्या कोई प्रभाव है जिसे आप सकारात्मक मानते हैं?
3. क्या कोई प्रभाव है जिसे आप नकारात्मक मानते हैं?
4. आपके देखभाल प्राप्तकर्ता के साथ आपका संबंध समय के साथ कैसे बदल गया है?
5. क्या आपके शारीरिक और मानसिक स्वास्थ्य पर कोई प्रभाव पड़ रहा है? यदि हाँ, तो कृपया विस्तृत करें।
6. क्या यह कभी आपको भावनात्मक रूप से प्रभावित करता है? यदि हाँ,
  - कैसे
  - सामना करने की रणनीतियाँ
7. क्या आपके सामने ऐसे विचार आते हैं जो आपको अपने भविष्य के बारे में चिंतित करते हैं? क्या आप अपने भविष्य को लेकर चिंतित रहते हैं ?

#### चुनौतियाँ और पुरस्कार:

1. देखभाल करने वाले की सभी जिम्मेदारियों के साथ, आप अपने व्यक्तिगत और सामाजिक जीवन का प्रबंधन कैसे करते हैं?

2. क्या आपके सामने कोई व्यावहारिक समस्या है या कोई चुनौतीपूर्ण समय है? (यात्रा, खाना पकाने, नहाने की चुनौतियाँ) यदि हाँ, तो आप उनसे कैसे निपटते हैं?
3. आपने अपने पूरे जीवन में अलग-अलग भूमिकाएँ निभाई होंगी, क्या आप उन्हें समय के साथ बदलते हुए देखते हैं? क्या भूमिकाओं या भूमिका संघर्षों के साथ कोई चुनौतियाँ हैं?
4. क्या कोविड-19 के दौरान आपको किसी विशेष चुनौती का सामना करना पड़ा?
5. क्या आपको लगता है कि चुनौतियों के साथ-साथ देखभाल करने के कुछ पुरस्कार भी हैं? (उदाहरण: कृतज्ञता का भाव)

#### स्व-देखभाल और मुकाबला:

1. आप अपनी स्वयं की देखभाल के लिए क्या करते हैं?
2. आत्म-देखभाल के साथ-साथ, क्या आपके कोई शौक या चीज़ें हैं जिन्हें आप करना पसंद करते हैं? यदि हाँ, तो क्या आप उनका पीछा कर सकते हैं?
3. आप अपने मानसिक स्वास्थ्य का कैसे खयाल रखते हैं? सामना करने की रणनीतियाँ।

#### समग्र रूप से विषय पर विचार:

1. भारत में वृद्ध वयस्कों की अनौपचारिक देखभाल पर आपके क्या विचार हैं? क्या यह कुछ अलग है जो हमारे भारतीय समाज में हमेशा होता आया है या यह कुछ नया है?

#### देखभाल प्राप्तकर्ता:

- 1) क्या आप इन गतिविधियों को बिना किसी की मदद के स्वयं करने में सक्षम हैं? यदि नहीं, तो किस प्रकार की सहायता की आवश्यकता है?

गतिविधियाँ	स्वतंत्र रूप से	सहायता की जरूरत है	आश्रित

स्नान			
तैयार हो रही हूँ			
बाहर जाना			
शौचालय			
बिस्तर से बाहर स्थानांतरण			
पेशाब को नियंत्रित करना			
खुद खिलाओ			
दाँत साफ़			
कपडे धोने			
दवाएं लेना			
धन का देख रेख			
अन्य			

## 2) प्राथमिक देखभालकर्ता कौन है?

### अपेक्षाएं:

1. आपकी देखभाल करने वाले से आपकी क्या उम्मीदें हैं?
2. आपके विचार में कोई व्यक्ति क्या कर सकता है / एक अच्छे देखभालकर्ता के रूप में अर्हता प्राप्त करने के लिए उसमें कौन से गुण और कौशल होने चाहिए?
3. अगर आप अपने देखभाल करने वाले के बारे में कुछ बदल सकते हैं, तो वह क्या होगा?

### प्रभाव:

1. समय के साथ आपकी देखभाल करने वाले के साथ आपका रिश्ता कैसे बदल गया है?
2. क्या आप अपने देखभालकर्ता के बिना एक पूरा दिन बिता सकते हैं? अगर हाँ तो कैसा लगता है?

3. क्या आपके सामने ऐसे विचार आते हैं जो आपको अपने भविष्य के बारे में चिंतित करते हैं? क्या आप अपने भविष्य को लेकर चिंतित रहते हैं ?

**विचार और रवैया:**

1. भारत में वृद्ध वयस्कों की अनौपचारिक देखभाल पर आपके क्या विचार हैं? क्या यह कुछ अलग है जो हमारे भारतीय समाज में हमेशा होता आया है या यह कुछ नया है?
2. जैसा कि हम भारत में जानते हैं, शहर में एक ही घर में बच्चों के साथ बुजुर्ग रहते हैं, जो वित्तीय और स्वास्थ्य सुरक्षा सुनिश्चित करता है। दूसरी स्थिति में वे एक अलग घर में अकेले रहते हैं या किसी पुराने देखभाल केंद्र में स्वतंत्र रूप से रहते हैं, बच्चों के साथ उसी शहर या अलग में रहते हैं। तो आपकी राय में, सबसे अच्छी देखभाल व्यवस्था क्या है?
3. एक विकल्प दिए जाने पर क्या आप व्यवस्थाओं को कुछ अलग करना चाहेंगे और वह क्या होगा?
4. वृद्ध देखभालकर्ताओं का जीवन कैसे बेहतर बनाया जा सकता है?
5. जब आप अन्य समकक्षों को भिन्न समर्थन प्रणाली वाले देखते हैं तो आपको कैसा लगता है?
6. वृद्ध लोगों (बुजुर्ग जोड़ों या वृद्ध वयस्कों की दो पीढ़ी) के लिए आपकी क्या सलाह होगी जो अकेले रह रहे हैं?

7. क्या आपको लगता है कि लिंग किसी भी तरह से इस सेटिंग में भूमिका निभाता है? उदाहरण;
  - महिलाएं किन अतिरिक्त चुनौतियों का ध्यान रखती हैं?
  - क्या देखभालकर्ता के रूप में महिलाओं को कोई लाभ मिलता है?
  - क्या यह पुरुषों या महिलाओं के लिए अधिक कठिन है? कौन सा रोल ज्यादा चैलेंजिंग है?

**स्व-देखभाल और मुकाबला:**

1. आप अपनी स्वयं की देखभाल के लिए क्या करते हैं?
2. आत्म-देखभाल के साथ-साथ, क्या आपके कोई शौक या चीजें हैं जिन्हें आप करना पसंद करते हैं? यदि हाँ, तो क्या आप उनका पीछा कर सकते हैं?
3. नकारात्मक अनुभवों से निपटने के लिए आप कौन-सी रणनीतियाँ अपनाते हैं?

**चुनौतियां:**

1. आपके सामने कुछ ऐसी चुनौतियाँ हैं जिनका आप सामना करते हैं - दिन-प्रतिदिन के जीवन में, आपात स्थिति में, अन्य अवसरों में (स्वास्थ्य आपात स्थिति, स्थानों पर जाना, सामाजिक जीवन)
2. क्या परिवार के किसी वृद्ध सदस्य द्वारा देखभाल किए जाने के कोई लाभ या अच्छी बातें हैं?
3. क्या कोविड-19 के दौरान आपको किसी विशेष चुनौती का सामना करना पड़ा?

सहायता:

1. इस स्तर पर वित्तीय सुरक्षा महत्वपूर्ण है। वित्त की देखभाल कौन करता है? क्या आपके पास कोई स्वास्थ्य बीमा है?

## Appendix C

### Kuppuswami Scale

Education of Head of Family	Score	Occupation of Head of Family	Score	Total per capita family income per month	Score		Socioeconomic Class	Total Score
Professional Degree	7	Professional semi professional clerical/shop skilled worker unemployed	10	48000 & above 24000-48000 18000-24000 12000-18000 Less than 12000	12		Upper Class	26 to 29
Graduate	6		6		10		Upper Middle	16 to25
Diploma			5		6		Lower Middle	11 to 15
12th & Less			4		4		Upper Lower	5 to 10
Illiterate			1		1		Lower	Below 5
Participants	Score	Socio-economic Class						
B01 & N001	12	Upper Middle						
S02 & R002	27	Upper Class						
R03 & S003	18	Upper Middle						
E04 & M004	16	Upper Middle						
N05 & L005	21	Upper						

		Middle						
T06 & F006	20	Upper Middle						
M07 & M007	23	Upper Middle						
S08 & S008	28	Upper Class						
R09 & S009	24	Upper Middle						
G10 & P010	26	Upper Class						
R11 & M011	22	Upper Middle						
P12 & B012	17	Upper Middle						
N13 & K013	24	Upper Middle						
A14 & F014	20	Upper Middle						
ML15 & M015	27	Upper Class						
D16 & A016	21	Upper Middle						
V17 & Y017	25	Upper Middle						
A18 & J018	22	Upper Middle						
N19 & A019	24	Upper Middle						
Z20 & H020	20	Upper Middle						
S21 & L021	17	Upper Middle						
G22 & C022	22	Upper Middle						
H23 & S023	24	Upper Middle						



B24 & H024	19	Upper Middle						
H25 & H025	18	Upper Middle						