

## **Informal Care for Disabled and Elderly Population in Contemporary Sri Lankan Society**

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The role of the family in providing care is a historical and culturally rooted practice in Sri Lanka. Regardless of ethnicity, people are devoted to protecting the family; the most loving and warm nest for many people to spend their lifetime. Caring for people with disabilities and caring for elders have been an embedded practice in the Sri Lankan family system, however, due to rapid economic and socio-cultural changes a shift in the caring tradition has been observed. This study, therefore, aimed to explore the current informal caring practice among Sinhalese people with disabilities and elders. The study has focused on the care, cultural aspects of the care, social organizations, and the organized structure to provide care. In addition, social relations of care and the community support and assistance to provide care at the community level were also studied. The study was conducted in the Hapugoda No: 405 Grama Niladari Division in the Harispattuwa Divisional Secretariat of the Kandy District and the findings derived from the study are used to identify the significance of the informal care and the care providers, challenges faced by the care providers and the opportunities to enhance the informal care provisions in Sri Lanka.

**KEYWORDS:** Care Practices, Social Organization, Culture of Care

### **INTRODUCTION**

Informal Care in relation to disability and elderly is defined as “Care and support needs that is carried out by relatives, friends, acquaintances or neighbours, often without a contractual agreement or formal payment”

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(European Centre for Social Welfare Policy and Research, 2010). Informal care mostly take place at voluntary basis, however sometimes it can be argued that it has been the exclusive alternative that many families find in taking care of elders and people with disabilities. This study therefore primarily focused on the provision of informal care and the characteristics and nature of the informal care provision from the cultural aspect. According to the Australian Institute of Health and Welfare (2021) informal care givers are people who provide care to those who need it within the context of an existing relationship, such as a family member, a friend or a neighbour. Therefore, this study also determined to explore the situation of the informal care providers and the challenges and the realities they encounter. Sri Lanka has a strong sharing and caring legacy. The traditional helping system of “Nikam”, the practice of volunteering for those who need help, especially people with disabilities and elders was culturally entrenched. According to Herath (2004), the Sri Lankan tradition is rooted with a central value system, where individuals maintain close relationships with each other. The family system and the social organization of the family cared for each other, especially in child rearing and caring practices. The historical family identified in Sri Lanka is in the form of extended family, where individuals were tied by kinships and generationally lived together. Kinship pattern and the kinship network was much stronger and the kinship protected the people who lived together, sharing common resources.

The term ‘care’ is involved with love and affection in social work discipline and usually ‘care’ refers to the “act or process of looking after people by undertaking tasks that they are unable to do for themselves (Harris, *et al*, 2013, p:52). According to the definition, it is evident that ‘care’ target for those who need assistance and help at all times. However, this term has been criticized by many activists in the field of ‘Disability’. Care can be categorised as formal care and informal care. Formal care is the service or the assistance provided by the mix of service providers, including paid care givers, social workers, therapists, counsellors, disability assistants and so forth. Informal care refers to a range of emotional and instrumental supports provided by social networks, neighbours, friends and family members (O’Leary, *et al*, 2010, p:6). Informal care is more associated with emotional support, love, and affection than fulfilling a job role for a second party. Informal care on the other hand can be considered as a responsibility and accountability of the family members, closed relatives and sometimes the neighbours’ if they closely associated with concerned families in looking after elders and children.

Social Organization of Care According to the American Psychological Association (APA) Dictionary of Psychology (2022), is defined as, the complete set of social relationships among members of a society or other groups, which determine the structure of the group and the place of individuals within it. These relationships can be based on several variables: kinship, age, sex, area of residence, and in human beings, religion, matrimony, or common interests. Accordingly, the social organization of the Sinhalese culture and its influence on the provision of care is significant. In the most historic period, the care and the affection for the neediest was provided by the closed social networks. However, the development of private property ownership, interest on living separately, growth of urbanization as well as industrialization generate a society with the demand for 'care'. The mandatory family responsibility for care therefore takes a different form and generates an industry of care. Similar to the changes in the world, in Sri Lanka also there has been changes in the traditional informal care system due to following changes in the socio- political structure.

01. Colonization
02. 1977 Open Economy
03. Globalization
04. Global Pandemic

The above historical milestones transform the socio- political context in Sri Lanka, especially after the colonization, the traditional conventional helping system was changed as the new form of culture and tradition were incorporated within the country. Further the independence and the introduction of open economy escalated the urbanization, migration, foreign trade, and inclusion of private and non-governmental organizations in the Sri Lankan economy. The open economy facilitated and opened doors for women employments, women migration especially for middle income countries as domestic labourers. Moreover, the internal migration was increased in search of employments as well as women education was expanded and as a result the proportion of working women was increased. Women were promoted to acquire new social roles and status after the 1977 open economy. Indirectly the new move caused the changes in the informal care industry as the role of the women were changed and the gap was created within the family specially to look after elders, children and people with disabilities. Accordingly, the informal care work specially in looking after older

population and people with disabilities confined to assent the new social world and its strategies.

Ageing and Disability are world recognized social concerns. Rapid increase in longevity is caused due to advancements of the health system and the increase of the number of people with disabilities is due to the national and international war and changes of food and habits of people around the world. Recognition of new disability types (as an example identification of Breast cancer as a disability) are some of the reasons to counter the world attention on elderly and disabled people. Due to the prevalence of breast cancer in the US, the Social Security Administration (SSA) listed breast cancer as a disabling condition and a potentially qualifying disability. As a result, the neo-liberal market economy prepared well to supply the upbringing demand in many forms, and among them, the most amount of trends was observed in the formal care or in the paid care. Introduction of paid homes to look after elders and people with disabilities, train paid care workers in the care industry, care teaching and learning are few of the new reforms in the care. In addition, Diploma in Health Care, Elder Care, Diploma in working with senior citizens can be also recognized under neo liberal reforms in the care field. The government of Sri Lanka too adapted certain strategic measures to look after elders and people with disabilities by establishing elder care homes and homes for people with disabilities. On the other hand, the private sector also timely recognized the national and international demand and open admission paid care for people with disabilities and elders. Additionally, the Buddhist and especially Christian religious based organizations initiated to look after the needy through their religious teachings and practices. The Covid-19 pandemic created a new normal situation in the world and that also signified the informal care and formal care in protecting humankind from the Corona virus.

## **METHODOLOGY**

The study adapted the qualitative research design as the research problem of the study need to be explored from the perspectives of the informal care providers. The study location is the No: 405, Hapugoda Grama Niladari Division which is located in the Kandy District. The village is recognized with semi urban characteristics and great majority of the people of the village are low middle income Sinhalese Buddhists. Primary data were gathered through personnel interviews conducted with 10 families with elders and 05 families with people with disabilities. In addition, focus group discussion was

conducted with 10 members from the Village development society of the No:405, Hapugoda Grama Niladari Division. Key informant interviews were conducted with the Reverent of the temple, Development officer, Elders rights promotion officer and the Grama Niladari of the Village and one purposively selected care giver during the data collection. In addition, secondary data was gathered through reports and records particularly on the Hapugoda Grama Niladari division. The collected data was analysed through thematic analysis method and the recommendations and the findings deriving from the study will be used to enhance the social work interventions with care takers of disabled and elderly population.

## RESULTS AND DISCUSSIONS

No: 405, Hapugoda Grama Niladari Division is located 07 Kilometres away from the Kandy Municipality. The total number of population of the village is 1202. Among them 613 are females and 589 are males. The age distribution of the villagers are as follows.

**Table 1: Age Distribution of the Population**

Age Distribution	Number of People
0-5 Years	74
6-18 Years	216
19-60 Years	709
Above 60	203

*Source: Field Data, 2021*

**Table 2: Disabled Population of the Village**

Nature of the Disability	Number of PWDs
Quadriplegia	02
Mental Disabilities	02
Visually Impaired	01
Amputee	01
Other	03

*Source: Field Data, 2021*

Among the total population, pensions are received by 65 number of people and Public Senior Citizen Assistance is received by 63 elders. There were 02 individuals who received assistance for chronic illnesses.

**Table 3: Profile of the Respondents-Care Givers of PWDs**

<b>Sex</b>	<b>Age (years)</b>	<b>Civil Status</b>	<b>Family Members</b>	<b>Nature of the Disability</b>	<b>Relationship to the PWDS</b>
<b>Female</b>	61	Married	05	Mental Disability (Autism plus Down-syndrome male 24 years)	Son
<b>Female</b>	54	Married	05	Multiple Disability- 16 Years of Age Female Child	Daughter
<b>Female</b>	63	Married	06	Physical Disability- Amputee	Sister
<b>Female</b>	70	Widowed	02	Multiple Disability- 22 Years of Age Male	Son
<b>Male</b>	68	Widower	03	Mental Disability- 47 Years of age Male	Son

*Source: Field Data, 2021*

The above table explains the nature of the disability of the care receiver and the relationship status to the main care provider with relevant background information. According to the findings, it was reported that majority of the informal care givers are females bounded with family related duties and responsibilities. Almost all the respondents are Sinhalese, Buddhists and they have strong relationships with the temple of the village nonetheless the relationship of the care receiver with the religious institute and the participation for religious activities were minimal. Further, majority of them are married and are having more than 05 members in a family. Informal care takers were mostly the mother or father of the child, except in one identified case. As revealed, a disabled woman of 70 years of age is being looked after by her 63 year old sister who lives very close to her house.

#### **A. Background Information of the Care Givers**

All the respondents were unemployed and the identified 68-year male widower is a retired conductor of the Sri Lanka Transport Board, Kandy. As revealed, the disabled person's expenses for medication and the other requirements are being fulfilled by the family members. Moreover, the informal care taker has to manage the household work as well as the well-being of the PWDs. As explained by one mother who is 63 years of age. "I have to look after my nephew as well as my sister. Other children are scolding

me for going to take medication with my sister”, as revealed, this mother had to take her daughter’s child to the school and soon after, returns home to take her sister to injections for her leg. She sometime missed her breakfast and she expressed that “I have lost my weight and health condition due to the stress that I have”. As care giving is a physically and psychologically strenuous task, caregivers are often identified with poor health (Lin *et al*, 2019) As explained by one informal care giver, her children have separated and hardly visit home due to the mental illness of their brother. As explored, the mother of this male is the only person to look after him and tolerate distresses given by the child. The other children have asked the mother to institutionalized their brother and come and live with them. However, the mother totally rejected that idea and determined to help and assist the child until her death. She sometimes goes for daily paid work to sustain both. The child who is at the age of 16 with multiple disabilities is cared by her mother who is a health professional in the government sector. From the birth the child is under the paraplegic condition. She struggles a lot to manage her child’s health and to protect the families’ financial stability. The mother of this family hired a paid care giver from the neighbourhood to care the daughter during office time, and after she returned until the next day, all the work is carried out by the mother as this child could not even stand and walk.

### **B. Sense of Love and Affection**

As revealed and identified, majority of the informal care workers are having a great compassion towards their loved ones, and especially this was visible when it is mother or father of the child. The role of a mother and father is ascribed. The ascribed role is associated with socially constructed performances which are more challenging for parents with disabled children. As stated in one case study, the mother of the disabled child died due to a heart attack in 2021 October and the father had to take the responsibility of the mother. But, the sudden loss of the mother, who had been the child’s immediate care taker, and to whom the child was too attached to, made him so vulnerable and arrogant. Therefore, the father had to switch his traditional role as the father and had to be the second mother to this child. As affection was more powerful within these families. The informal care givers showed reluctant to send their children with severe disability conditions to institutionalized care. However, they received less support and facilitation from other family members.

### **C. Social Organization of Care**

Social Organization was mainly identified from the family, neighbourhood and relatives. The support for many informal care workers was received from the family and the neighbourhood also facilitated in many instances to look after the disabled child. However, this is not the same for adults with disabilities. In many instances, neighbours' willingness was high to look after children with disabilities when the mother or the care workers abstains. The neighbourhood of the village is tied by kinship. Hence close and tied relationships were observed among each other. Rather in neighbourhood where there are close relatives, it is closely knit. As an example, they share their food with close families in the vicinity and specially the concern was given on the protection of the disabled child. They mostly keep an eye on the children with disabilities. Majority of the informal care givers appreciate the support rendered by the neighbours in non-material and material form than with family members.

### **D. Culture of Care for PWDs**

The care for people with disabilities was seen as a merit. A merit which the informal care givers earned during their birth. As mentioned above, majority of these respondents were Sinhalese Buddhists and they believed that being disabled is caused due to the fate of life and the destiny of life. There were mainly two types of fate they collectively agreed and believed.

- Destiny or the Fate of the Care Giver
- Destiny or the Fate of the Caretaker

Fate is shared by the informal care provider and the receiver. As one stated during the personnel interview: "This is the Karma of both, the child and myself, both have done bad to someone in last birth, so we have to pay for it". The family members believed karma on top of everything along with medical reports. The respondent who is a graduate and a health professional also was not ready to accept the fact that her child has a neurological impairment, and she also believed this as a part of their Karma in life. The neighbourhood was identified as one of the main resource providers as physical as well as non- physical help was received from the neighbours. Food sharing practices, caring the PWDs during emergency, provision of financial assistance were significant for many respondents, in addition, to the great advantage they receive from neighbours which was the mental support during an emergency, especially in deaths and illness of a close family members, neighbours supported them to share their sympathy and supported



members to share the loss of the family member. As revealed by one respondent, a 24 year multiple disabled child with autism spectrum disorder was having sexual desires and he used depraved words and used his organs to get sexual satisfaction. This has been a secret of the family and subsequently, the family members visited a psychiatric doctor to receive medication and the young male was advised to undergo a medication process. However, this incident was shared by the mother of the child with a close neighbour and this message passed to many of the neighbours in the village and the child and the mother had to face certain oppressive situations in public places.

### **E. Background Details of Elderly Care Givers**

According to the sample of the study, 10 elderly informal care takers identified and conducted a focus group discussion and three personal interviews from the selected participants. There are 203 of elderly in the Hapugoda Grama Niladari division. Among them majority of the elders are females, and they receive home based care from the informal care givers. It is an obvious fact that self-care becomes declined with the old age. Song et al (2020) mention that "The ability of older people to provide self-care decreases with old age as they decline in physical and cognitive functions and develop chronic conditions. Hence, the assistance become essential. As identified from the findings majority of the elders do receive the support from care givers and informal care givers are mostly females, either daughter or the daughter in law of the family. There were 10 elderly care takers who were purposefully identified to collect data. The main selection criteria were the age limit of the elderly males and females. Those who are above 65 years of age represent the sample.

### **F. Feminization of Elder Care**

Majority of the women work as informal care givers while fulfilling the roles and responsibilities of a family. The triple burden of the womanhood identified from the findings, the family responsibilities, economic responsibilities and the social responsibilities have to be fulfilled by the mother of the family. Women are inherently gifted with care, affection and love. Traditionally, caregiving responsibilities were the responsibilities of females of the family ((Lin *et al*,2019). This belief had forced women to take the informal care takers role. As identified, two daughters in law identified in the study had quit their jobs to care their children and look after the elderly at home.

### **G. Sandwiched Generation**

Burke et al, (2017) explains sandwich generation as, the challenge of balancing work and multigenerational care giving responsibilities as an increasing number of employed women and men raise young children. Further they support adult and children. Moreover, care for ageing parents while managing their own household and work responsibilities. The levels of employment and education of women have increased over the last few years in the world as well as in Sri Lanka. However, in this study almost all the care takers are home-based, and they have not been employed for a longer period of time; some have quit jobs due to the responsibilities associated in the family life. Percentage of elderly population has almost doubled during the period from 1981 to 2019 according to the Annual Health Statics, 2019, Sri Lanka.

### **H. Limitation in the Social Life**

Due to the responsibilities associated with elders and children, many informal female care givers have sacrificed their social life. They have omitted social gatherings, abstained from family trips, limited participation in village level gatherings (mostly the husband participates for funerals, arms giving and weddings). The informal care taker has confined her time to stay home to look after the elderly and there were certain disputes among the husbands and wives. However, the disputes hardly progressed to a conflict due to strong family relationships and family unity. As stated by one informal care giver (38-year-old daughter in law) "There are arguments between myself and my husband due to the burden I have in looking after his mother, I hardly find time to visit my parents and treat them, I even do not have money, but I bear everything to protect family life because we do everything not for us but for children". As explained by Bialon & Coke, (2012 p :212), "caregivers identified the presence and severity of behavioural problems and poor functional status as stressors to their care giving burden".

### **I. Cultural aspect of Elder Care**

As identified, the great majority of villagers are Sinhalese Buddhist and many of them are relatives and landowners from the heredity. There were mainly 04 caste groups identified in the village and the following terms are popular among villagers to name relevant caste groups Rate- Govigama, Bodiwansha. Berawa, Pali-Washermans/Radha. These groups lived separately in the village but they lived in harmony but no cross caste marriages were done among member villagers but of course many cross caste marriages were done outside the village. Regardless of the caste,

people believe that taking care of elders specially parents is a responsibility of the children and the one who lives in “Mahagedara” (The house where your parents lived during the old aged) had to take the main responsibility rather than other children of the family. There were 03 temples in the village and one represents the Amrapura Nikhaya and the rest of the 02 temples represent the Siyam Nikhaya. The teaching of these temples and the religious practices made the villagers to care of their old parents and many of the families accepted it as a responsibility. However, the only elderly who was unmarried with OCD syndrome was harassed by the Sister in law, mentally and physically. This woman has expressed his oppression within the family to many neighbours around and she received the support from neighbours during emergencies specially when she got sick. However, the cultural norm of the village regarding taking care of elders are more positive and constructive and there are no disputes reported to the GN of the village.

#### **J. Social Organization of Elder Care**

Many of the elders are looked after by the family members and children. However, there were instances where they received the paid care workers' assistance during the hospitalization of the elderly mother or father. Especially during the hospitalization many families of the village used to hire a paid care worker to stay with the parent, but a few with very low economic status used to stay with the elderly mother or father. As stated by one informal care giver, “We do not go to stay with the mother during the hospitalization, because if I stayed, no one is there to cook and look after my children. Even husband cannot stay as he has to go for work and earn. If not, the whole family will face problems”. Accordingly, getting a service of a paid care worker during the hospitalization is a practice of many middle class families in the village but not always with families with low economic status.

#### **CONCLUSION**

According to the findings of the study, it was identified that, villagers who lived in Hapugoda GN division accepted and practiced the traditional Buddhist teaching of caring elders and people with disabilities as a merit for their next birth. The religious teaching of karma and rebirth has made them to be devoted for care giving. However, the care giving has been the main responsibility of women rather than men and this social learning has been passing from one generation to another. Feminization of care therefore is a problem in the village. Further, this belief and practice hindered the social relationships of many women limiting their participations and contribution. The

intervention from the field level officers is minimal in the village and there are more opportunities for community based social workers to intervene to develop the well-being of the informal care workers at family level.

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