Bystanders' Perspectives on the Provision of Informal, Hospital-Based Care to Bedridden Patients with Cancer in Sri Lanka

B. Sunil S. De Silva

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BYSTANDERS’ PERSPECTIVES ON THE PROVISION OF INFORMAL,
HOSPITAL-BASED CARE TO BEDRIDDEN PATIENTS WITH CANCER IN
SRI LANKA

BY

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BYSTANDERS’ PERSPECTIVES ON THE PROVISION OF INFORMAL, HOSPITAL-BASED CARE TO BEDRIDDEN PATIENTS WITH CANCER IN SRI LANKA

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ABSTRACT

Due to the nursing shortage in Sri Lanka, patients need informal caregivers, known as bystanders, to help provide patient care. This study described bystanders’ perspectives on informal, hospital-based care to bedridden patients with cancer in Sri Lanka. In this qualitative descriptive study, 17 bystanders at Apeksa/Cancer Hospital, Sri Lanka, were recruited using snowballing sampling. Data were collected through telephone interviews and analyzed using content and thematic analyses. Findings showed that paid and unpaid bystanders cover all caregiving tasks with minimum interaction with nurses. Unpaid bystanders described the need for same-sex bystanders and additional help with patients’ mobilization and specialized care. Paid bystanders discussed sleepless nights’ effects, bullying, and monopoly. Recommendations include the provision of a bystander for every bedridden patient, basic facilities (adequate sleeping and sanitary facilities), quality foods, and caregiver training. Government-level policies are needed to accept the bystander service to improve quality patients care in Sri Lanka.
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CHAPTER 1
INTRODUCTION

This chapter introduces the dissertation study of bystanders’ perspectives on the provision of informal care in a cancer hospital in Sri Lanka. It starts with a “Statement of the Problem” and further elaborates the problem by reviewing Sri Lankan demographics, the Sri Lankan health care system, nursing in Sri Lanka, and the role of the bystander in the cancer hospital setting. It concludes with the research questions addressed by this study.

Statement of the Problem

The study setting is in Sri Lanka. Sri Lanka is a small island in the Indian Ocean located off the southern tip of India. Even though the landmass of Sri Lanka consists of 65,610 square kilometers, its population is more than 21 million (Department of Census and Statistics-Sri Lanka, 2018). Sri Lanka gained an exceptional position in South Asia as one of the first developing countries to provide universal free health coverage for the entire nation (Samarage, 2006). Rameez (2018) further highlighted that this small, lower-middle-income country, which is still developing, claims an impressive health care system. Equal to many upper-middle-income countries in terms of life expectancy and indicators for neonatal, maternal, and mortality rates for children under five years, Sri Lanka appears well placed to reach universal health coverage (UHC), one of the United Nations’ important Sustainable Development Goals (SDGs) (Rameez, 2018).
According to the World Health Organization (WHO) (2019), *universal health coverage* is a system in which all persons can use the quality promotive, preventive, curative, rehabilitative, and palliative health care services they need, while also confirming that the use of these services does not expose the user to financial hardship. The Sri Lankan health care system offers these services free of charge to every citizen of the country at the point of delivery. However, its overall high standards often direct attention away from certain prevailing gaps that should be addressed if we are to achieve true universality in health care (Rameez, 2018). In reality, many of the country’s households (60%) are forced to spend their own money for some surgical necessities, drugs, laboratory tests, specialized treatments, and medical investigations (Kumara & Samaratunge, 2016). Kasthuriratne and Sanjeewa (2015) pointed out that hiring or providing an informal caregiver, who is known as a ‘bystander,’ to look after the patient during the hospital stay is not only a significant economic burden for the patient, but also for their entire household.

A severe shortage of nurses and support staff in Sri Lanka is one of the major reasons why bystanders are required to look after and provide care to patients admitted to the hospital. According to the Ministry of Health Nutrition and Indigenous Medicine (2017), the total number of nurses in Sri Lanka in 2015 was 42,420. There were 185 nurses per 100,000 population in 2014 and 202 per 100,000 in 2015. In Sri Lankan health care settings, many patients who lack resources are seen in a nursing ward, which may not have an inadequate number of nurses. This nursing shortage, combined with a large number of patients, creates a chaotic situation in the hospital setting, where already heavy
workloads are increasing, sometimes forcing task-oriented nursing (B. S. S. De Silva & Rolls, 2010).

A bystander is a person who stands near and watches something happen, but who is not directly involved in the event (Cambridge Dictionary, 2019). However, as will become apparent, bystanders in the health care settings described in this dissertation do much more than “stand near and watch something happen”; they provide significant care to the patient. According to Pallium India (2019), a bystander is a relative who endlessly stands by anyone who is admitted to the hospital. He or she is not expected to sit, let alone lie down. Not only relatives act as bystanders; many bystanders are available for hire in Kerala in India (Karmakerala, 2017). The author further states that as many families shrink in size, sparing one person from the family is unthinkable to many, so bystanders-for-hire are necessary. Kasthurirathne and Sanjeewa (2015) also point out that some patients do not have close relations or older children who could take on the bystander role. In that context, they have to hire an outside person. Most hospitals will not permit more than one bystander to be with a patient, and that person is almost always busy (Pallium India, 2019). This is the same in Sri Lanka. Although there is a lack of literature on the subject in Sri Lanka, there are bystanders who are relatives and others who are hired persons. These bystanders are with each and every patient who need support or informal care for their day-to-day activities, such as personal hygiene and eating, especially in public hospitals. When it applies to palliative care patients who have a life-threatening illness and need end-of-life care, the role of the bystander is crucial.
In summary, due to the shortage of nurses and support staff in the existing public hospital setting in Sri Lanka, nurses have to focus on task-oriented nursing and do not have time to provide patient-centered, individualized quality care for patients. Hence, most patients need an informal caregiver known as a bystander to help them complete day-to-day activities; this is especially true for palliative care patients who are admitted to these hospitals. These bystanders are either patients’ family members or they are hired. Most families like to keep a family member as a bystander as much as possible due to socio-cultural bonds and religious obligations. This strong bond among family members due to moral and religious obligations is the framework of Buddhism and Eastern societal expectations; affection between the elderly and their loved ones also motivates relatives to serve as bystanders in wards in the hospital setting (B. S. S. De Silva & Rolls, 2010; Watt et al., 2014).

However, the type of the bystander and the care they provide is still not clear in the Sri Lankan context. It is of paramount importance to study the provision of care by bystanders, with special reference to patients who need palliative care in Sri Lanka.

**Sri Lanka**

Sri Lanka is a small island in South Asia, similar in size to Ireland (Williams, Chandler, Ranwala, De Silva, & Amarasinghe, 2001). It is located off the southern tip of India in the Indian Ocean to the southwest of the Bay of Bengal and to the southeast of the Arabian Sea. Its landmass consists of 65,610 square kilometers, with a 430-kilometer diameter from north to south; at its widest, it is 225 kilometers across. There are also
many smaller islands around the main island (Department of Census and Statistics-Sri Lanka, 2018). Although Sri Lanka is a small country, it has a large population of 21.4 million people (Department of Census and Statistics-Sri Lanka, 2018). Sri Lanka can claim a long history of civilization based on agriculture and irrigation, dating back more than 2,500 years (K. M. De Silva, 2005). The name of the country transformed during the colonial period of the United Kingdom from ‘Sinhalaya’ to ‘Ceylon’ in the English language, or ‘Lankawa’ in Sinhalese language (K. M. De Silva, 2005). After gaining independence from the United Kingdom in 1948, the country name was changed to present Sri Lanka in 1972 (K. M. De Silva, 2005).

Historically, the group of people known as ‘Indo-Aryan’ who migrated from India in the 5th century B.C. came to form the largest ethnic group in Sri Lanka today; they are now called the ‘Sinhalese’ (K. M. De Silva, 2005). According to available statistics, the Sinhalese community comprised 74.9%, of the population in 2012 (Department of Census and Statistics-Sri Lanka, 2018). The rest of the population was Sri Lankan Tamil at 11.2%, Sri Lankan Moors at 9.2%, Indian Tamil at 4.2%, and others at 0.5%. Tamils, the second-largest ethnic group in Sri Lanka, originally came from the Tamil region of India and emigrated between the third century B.C. and A.D. 1200. They comprised 15.6% of the population (4.2% Indian Tamil and 11.2% Sri Lankan Tamil). The Tamils are primarily Hindu and the Sinhalese are mostly Buddhist (69.1%) (Department of Census and Statistics-Sri Lanka, 2018).

According to the Department of Census and Statistics-Sri Lanka (2017), Sri Lanka is a multi-ethnic, multi-linguistic, and multi-religious country. The multi-ethnic
community includes Sinhalese, Tamils, a small group of Sri Lankan Muslims, and other unspecified ethnic groups. Sri Lankans are multi-linguistic; the official and national language, Sinhalese, is spoken by 74% of the population, and Tamil, also considered as the national language, is spoken by 18%. English is usually spoken in the government and is spoken proficiently by about 10% of the population. Sri Lankans are also multi-religious, with Buddhism being the most prominent religion. Furthermore, approximately 8% of the population is Muslim, 7.1% is Hindu, 6.2% is Christian, and 10% are unspecified (Department of Census and Statistics-Sri Lanka, 2017). Although the Sri Lankan population is diverse, all are considered Sri Lankans and are eligible to have equal rights in each sector, including their right to have quality, equitable, and affordable health care. However, many studies and reports have highlighted that, due to many reasons, including social determinants of health, health disparities are still common in Sri Lanka (Caldwell, Gajanayake, Caldwell, & Peiris, 1989; Department of Census and Statistics-Sri Lanka, 2017; Ministry of Health Nutrition and Indigenous Medicine, 2017).

Sri Lanka is a lower-middle-income country with a gross domestic product (GDP) per capita of USD 4,073 in 2017 (Central Bank of Sri Lanka, 2018). Following 30 years of a brutal civil war that commenced in 1983 and ended in 2009, Sri Lanka’s economy grew at an average of 5.8% during the period of 2010-2017 (The World Bank, 2019). The GDP in Sri Lanka expanded by 3.8% in the first quarter of 2017 compared to the same period in 2016. The GDP growth rate in Sri Lanka averaged 6.07% from 2003 until 2016, reaching an all-time high of 16.12% in the first quarter of 2012 and a record low of 0.48% in the fourth quarter of 2013. Hence, economic growth has translated into shared
Prosperity, with the national poverty headcount ratio declining from 15.3% in 2006/07 to 4.1% in 2016 (Central Bank of Sri Lanka, 2018). According to the Sri Lanka National Health Accounts 2013, health expenditures accounted for 3.2% of the GDP of the country for that year. Per capita health expenditure was 12,636 Sri Lankan Rupees (LKR) (97.20 USD). The report recognizes that the government is the main financier of health care expenditures. The government was responsible for providing 55% of total current health care expenditure, while households’ out-of-pocket expenditures contributed 45% (Ministry of Health Nutrition and Indigenous Medicine, 2017). Therefore, equality is still questionable.

A major tsunami in late December 2004 took about 31,000 lives, left more than 6,300 people missing, and 443,000 people displaced, and demolished an estimated $1.5 billion in property in Sri Lanka (Department of Census and Statistics-Sri Lanka, 2017). This tragedy influenced all parts of Sri Lankan society, including the health care system. At the same time that Sri Lanka was dealing with the tsunami disaster, the struggle by the Tamil Tigers/terrorists in the north and east for an independent homeland continued to cast a shadow over the Sri Lankan health care system and economy (Central Bank of Sri Lanka, 2018).

Due to the free health care system, life expectancy at birth is currently 75 years (2015), the crude birth rate is 15.6 births/1,000 population (2016), and the crude death rate is 6.2 deaths/1,000 population (2016) (Department of Census and Statistics-Sri Lanka, 2018). However, according to the Department of Census and Statistics, there are major health problems that are influenced by the Sri Lankan health care system, such as
malnutrition, addiction to liquor and drugs, non-communicable diseases, elderly population, and suicides. These further increase the number of hospital inpatients.

**Sri Lankan Health System**

The Sri Lankan health care system is composed of several different systems of medicine, including western, Ayurvedic, Unani, Siddha, homeopathy, and acupuncture. Of these, western or allopathic medicine is the main sector catering to the needs of most Sri Lankans (Ministry of Health Nutrition and Indigenous Medicine, 2017). Western medicine is provided through both the public and private sectors.

The public health care system is a free government service under the Ministry of Health, Nutrition and Indigenous Medicine. It comprises both western and Ayurvedic systems and provides the entire range of preventive, curative, and rehabilitative health care. The public sector provides the majority of inpatient care, nearly 95%, delivering a safety net to the people of the country (Ministry of Health Nutrition and Indigenous Medicine, 2017). According to the Ministry of Health, Nutrition and Indigenous Medicine, more than six million Sri Lankans were hospitalized in 2015. However, outpatient care is divided almost equally between the public and private sectors. A total of 55 million public sector outpatient visits occurred in 2015.

Large public hospitals experience overcrowded outpatient departments (OPDs), long waiting queues, and more than 100% occupancy rates; these problems are worsened by the lack of a firm referral system and the bypassing of small community health centers (Caldwell et al., 1989; Dilrukshi, Nirmanamali, Lanel, & Samarakoon, 2016). In addition,
high patient loads contribute to cursory consultations at public OPD facilities, causing many patients to seek outpatient treatment at private hospitals, clinics, and pharmacies. Further, patients usually choose to visit public doctors practicing privately outside official public hours.

Kumara and Samaratunge (2016) highlighted variations in the distribution of health care in Sri Lanka and identified underserved areas. According to the authors, the marked concentration of hospitals displays an urban bias in the distribution of health care facilities in Sri Lanka. The authors further pointed out these services are not accessible to all, but they are generally affordable because health care services are provided free of charge. However, although people initially contact public hospitals, they end up in the private sector, paying out of pocket for laboratory tests, drugs, and medical devices, thereby increasing the burden on the rural population (Rannan-Eliya et al., 2015).

Under-funding of the government health sector is widespread and has started to worsen in recent years, with the expenditure relative to GDP dropping. Health expenditure as a share of GDP of Sri Lanka fell gradually from 4.14 % in 2001 to 2.97 % in 2015 (Central Bank of Sri Lanka, 2018). The burden of under-funding has mainly affected preventive and promotive services and reduced the levels of curative facilities due to the inadequacy of guidelines and standards for prioritization. According to Kumara and Samaratunge (2016), unnecessary demand is leading to widespread control, especially at tertiary-care hospitals, as patients tend to avoid poorly funded homegrown facilities with poor quality of service.
The government health sector is characterized by a very busy and overcrowded system of national, provincial, general, and base hospitals and a widely spread network of district hospitals and health care units operating at lower levels of utilization and occupancy (Ministry of Health Nutrition and Indigenous Medicine, 2017). According to the WHO (2018), management of the health care system needs a clearer conceptual basis for coordination of health services, coupled with adequate resource allocation and the strengthening of existing health care institutions island wide.

**Nursing in Sri Lanka**

Nursing education in Sri Lanka is mainly conducted under the Ministry of Health. There are 17 nursing training schools (NTS) all over the country and attached to the teaching and general public hospitals (Ministry of Health Nutrition and Indigenous Medicine, 2017). Sri Lankan nurses need to complete three-year General Nursing Diplomas from an NTS to become a registered nurse and to get employment at a public hospital under the Ministry of Health, including the Cancer Hospital, which is the setting of this study.

Post Basic College of Nursing (PBCN) is the only government higher education institute for registered nurses in the country, attached to the National Hospital of Sri Lanka (NHSL), under the Ministry of Health. It mainly produces nurse managers, nurse educators, and public health nurse managers to serve all over the country, focusing on providing middle-level leadership among nurses to uplift the health care status of the nation. Post-registration training in nursing specialties, such as cancer nursing, is
currently not available in Sri Lanka. However, PBCN conducts short courses for registered Sri Lankan nurses to sharpen specified required skills in various specialties, such as operating theater nursing and intensive care nursing (Ministry of Health Nutrition and Indigenous Medicine, 2017).

Sri Lankan nurses have been involved in delivering health care services by caring for patients, preventing illnesses, and promoting the health status of the people throughout the history of nursing in Sri Lanka. However, the nursing profession has been considerably delayed in asserting its professional status within the Sri Lankan health sector (B. S. S. De Silva & Rolls, 2010; Jayasekara & McCutcheon, 2006).

Medical doctors command a high standing within the professional sector and especially the health care sector in Sri Lanka. The concept of producing graduates in related health fields such as nursing, radiography, pharmacy, and physiotherapy has been a low priority and received little encouragement from the entrenched medical profession (B. S. S. De Silva & Rolls, 2010; Fernando, 1999). After a considerable delay to absorb the nursing graduates from Sri Lankan universities, 94 nursing graduates were recruited to the current nursing workforce of 42,420 under the Ministry of Health in 2015 (Ministry of Health Nutrition and Indigenous Medicine, 2017).

There has been minimal effort to enhance the nursing workforce and to improve the standards of nursing education primarily due to the inadequate involvement of those responsible for improving health services in Sri Lanka. Nursing services and nursing education in Sri Lanka are under scrutiny because nurses today are increasingly concerned about their professional roles, education, and status (B. S. S. De Silva & Rolls,
2010; Jayasekara & McCutcheon, 2006). Research shows us that nurses need a solid university-based education, assertiveness skills, specialized knowledge, skills in different fields of nursing, including oncology, and technical competence to work within the rapidly changing health care world in Sri Lanka to enhance the nursing workforce. Sri Lanka has a low density of nurses (16.4 per 10,000 population) when compared to developed countries such as the United Kingdom (88.0) and Canada (92.9), but is comparable to other countries in the region, such as Maldives (50.4), Indonesia (13.8), India (17.1), Myanmar (10.0), and Pakistan (5.7) (World Health Organization, 2015). Therefore, nurse shortages are greatest in Sri Lanka, where a lack of nurses’ results in a limited capacity to meet health needs and establishing a need for bystanders in Sri Lankan hospitals.

**Being the Bystander**

*Bystander* is the word used in most Asian countries, including Sri Lanka, for an informal caregiver who looks after patients in the hospital. According to Pallium India (2019), *bystander* is a dreadful title that can be depersonalizing to a human being, and the medical system is hardly aware of the implied insult. However, in the literature, this term refers to an unpaid family member, friend, or neighbor who provides care to an individual who has an acute or chronic condition and needs assistance to manage a variety of tasks, from bathing, dressing, and taking medications to tube feeding and ventilator care (Reinhard, Given, Petlick, & Bemis, 2008). This study will consider the bystander to be a type of informal caregiver in the hospital.
According to Amiresmaili and Emrani (2018) concerning the shortage of health care providers and staff in hospitals in Sri Lanka, nurses have less time to take care of each patient. Therefore, using informal caregivers as an implicit strategy to overcome the nursing shortage and to reduce hospital costs seems to be beneficial. In a study in Greece, Lavdaniti et al. (2011) highlighted that family members were forced, unofficially, to stay with patients at their bedsides for many hours to assist with their care. However, as family sizes have shrunk, family members find it hard to be available for hospitalized patients due to many reasons, including economic commitments to the family (Hui, Wenqin, & Yan, 2013). Therefore, paid caregivers may provide inpatient bedside nursing care, especially for chronically ill patients and those patients with self-care deficits. The role of the hospital patient caregiver/bystander, therefore, has become a source of employment for which there is a great demand in Asian countries, including Sri Lanka.

Critically ill patients, including patients with cancer in a palliative care setting, may depend heavily on bystanders to receive assistance and care during hospitalization. Bystanders spend a substantial amount of time interacting with their patients while providing care in a wide range of activities (Reinhard et al., 2008). Hui et al. (2013) pointed out that the role of caregivers/bystanders includes a huge amount of bedside care, particularly regarding the maintenance of personal hygiene, feeding, changing positions, and managing excrement. Further, from the patients’ point of view, the presence of a bystander decreases anxiety and increases satisfaction (Amiresmaili & Emrani, 2018).

From the bystanders’ perspective, they often feel unprepared to provide care, have inadequate knowledge to deliver proper care, and receive little guidance from formal
health care providers (Scherbring, 2002). When it comes to palliative care in the cancer setting, the situation is worse because the care of cancer patients is lengthy, time-consuming, and multidimensional. Caring for a patient with cancer physically and psycho-emotionally affects the health of bystanders over time (Hassankhani, Eghtedar, Rahmani, Ebrahimi, & Whitehead, 2019). Some bystanders experienced physical problems, including stomach pain and sleep disturbances, because of the psycho-emotional stress of providing constant care. In addition, psychological distress, depression, anxiety, and social isolation were also identified as results of psycho-emotional stress (Applebaum & Breitbart, 2013).

Further, Kim, Kashy, Spillers, and Evans (2010) pointed out that problems relating to bystanders’ daily lifestyles, including their capability to balance their own personal care with the demands of caregiving, are most common in the early stages of caring life. Impacting the situation further, factors such as poor living conditions in hospital wards, long-term separation from family, an unstable job, and low income all contributed to a high rate of caregiver turnover. This high level of turnover is associated with a reduced quality of care (Hui et al., 2013).

**Significance of the Study**

This study is of significance due to a number of reasons. This is the first study of bystanders in Sri Lanka that identifies the bystanders’ perspectives on the provision of informal, hospital-based care to bedridden patients with cancer. Therefore, the findings from this study can inform future research studies related to bystanders. Further, the
recommendations made by bystanders can indirectly inform the quality of health care for patients with cancer. Ultimately, the overall findings from this study can help to develop the quality of health care delivery not only in developing countries, but also in some developed countries that use bystanders.

**Conclusion**

It was evident that all critically ill patients, including cancer care patients, in the hospital need bystanders in many countries in the world, particularly Asian countries (including Sri Lanka). The main push behind the role of the bystander is a severe shortage of nurses in many countries, including Sri Lanka. The shortage of nurses and a large number of patients create a hectic situation in the hospital setting, which increases nursing workloads and forces nurses to focus their practice on essential task-oriented nursing in the hospital ward. Family-related bonds and Buddhism-related obligations also encourage the use of bystanders in inpatient care, especially in Asian countries like Sri Lanka.

Therefore, the bystander plays a key role in inpatient care. The bystander is known as the informal caregiver or family caregiver; most often, they are a family member, relation, close neighbor, or friend of the patient or his/her family. However, due to limited numbers of family members who often have significant family commitments, many families try to hire a person as a bystander. As such, there are two main types of bystanders: paid and non-paid. However, little is understood about whether Sri Lankan bystanders are paid or not, particularly in cancer-related hospital settings, due to a lack of
studies conducted on this topic. It is of paramount importance to study bystanders’ perspective on the provision of informal care in a cancer hospital in Sri Lanka.

**Research Questions**

The purpose of this study was to explore bystanders’ perspectives on the provision of informal, hospital-based care to bedridden patients with cancer in Sri Lanka. Findings from this study addressed the following questions:

1) What are bystanders' perspectives on providing informal care for bedridden patients with cancer in hospital settings in Sri Lanka?

2) What are the types of interactions bystanders’ have with nurses?

3) What are the recommendations of bystanders to improve informal care for bedridden patients with cancer in hospital settings in Sri Lanka?

Bystander service has been common in Sri Lanka for many years, but it is difficult to find literature that has studied this field, especially in a cancer-related palliative care setting. Although bystanders are available at most public hospitals with bedridden patients who require bedside self-care, no studies have been done in Sri Lanka. It was envisioned that a study in this area would help gather information and provide insight into bystanders and their role, especially since proper informal care service is yet to be developed in Sri Lanka. Hence, this study provided a deeper understanding of bystander’s experiences with the care that inpatients expect from the public hospital, including a cancer hospital in Sri Lanka. Such knowledge is particularly crucial to inform
nursing practice and develop policy and practical supports for the bystander role in Sri Lanka. However, it is important to recognize that this is a study of self-report by bystanders and not an evaluation of nursing and medical care provided.
CHAPTER 2
THE LITERATURE REVIEW

The focus of this literature review directly relates to the main purpose of this study, to explore bystanders’ perspectives on the provision of informal, hospital-based care for bedridden patients with cancer in Sri Lanka. Three research questions were formulated to achieve the main purpose of the study accurately and effectively; 1) What are bystanders' perspectives on providing informal care for bedridden patients with cancer in hospital settings in Sri Lanka?; 2) What are the types of interactions bystanders have with nurses?; and 3) What are the recommendations of bystanders to improve informal care for bedridden patients with cancer in hospital settings in Sri Lanka?

Literature published between the years 2014 and 2019 was retrieved for this review and a small number of relevant articles dated before 2014 were also included due to their importance about bystanders’ perspective on the provision of care in Sri Lanka. The researcher reviewed Asian regional literature as well as literature from Western countries, such as the United States and European countries. Material for the review was obtained from several sources, including books, peer-reviewed journals, and electronic databases such as PubMed, PubMed Central, CINAHL, Science Direct, and Google Scholar. Published research on palliative care, cancer-related palliative care in Sri Lanka, bystanders for cancer-related palliative care, types of bystanders, the care provided by bystanders, challenges faced by bystanders in providing care, bystanders’ type of interactions and communication with nurses, and the recommendations of bystanders to
improve informal care were accessed and reviewed. Further, the limited informal advocacy literature on improving conditions for bystanders was also reviewed.

**Palliative Care**

Palliative care is an approach that improves the quality of life for patients and their families facing issues associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual (World Health Organization, 2019). According to the International Association for Hospice and Palliative Care (2019), palliative care is active holistic care that focuses on individuals across all ages with serious health-related suffering due to severe illnesses, and especially those near the end of life. Further, it aims to improve not only the quality of life of patients, but also their families and caregivers. Hence, caregivers or bystanders are also part of palliative care.

According to Clark (2007), palliative care has developed rapidly since the late 1960s based on the groundbreaking work of Cicely Saunders, who was working as a nurse in the 1940s and was the founder of St Christopher's Hospice in London. She is generally recognized as the founder of the palliative care movement (Baines, 2011). Her pioneering work was especially focused on drawing attention to the end-of-life care needs of patients with advanced cancer (Clark, 2007). Clark further pointed out that palliative care began to be demarcated as a subject of activity in the 1970s and came to be associated with care provided by a multidisciplinary team for the physical, social,
psychological, and spiritual needs of patients with a life-threatening illness. Even though palliative care services have developed in many settings and have often been closely related to oncology at its initial stage, it gradually has spread to different patient groups with life-limiting illnesses and is no longer limited to cancer (Baines, 2011).

Currently, palliative care is considered one of the crucial elements of each country’s health care system (Ansari et al., 2019). In most developed countries, up to 80% of individuals who die due to life-threatening illnesses could benefit from palliative care much earlier in their illness (Murtagh et al., 2014). Although palliative care in community care settings may be related to lower costs than palliative care in hospitals, studies in 33 developed and developing countries highlighted that most individuals wish to die at home (Gomes, Calanzani, Gysels, Hall, & Higginson, 2013). However, it was further noticed that a growing number of patients with chronic diseases in developed countries are dying in the hospital (Pivodic et al., 2016). Tung et al. (2019) highlighted that nearly half of all cancer deaths were reported in hospitals. Furthermore, Tanuseputro, Budhwani, Bai, and Wodchis (2017) pointed out that, among all decedents in Ontario, Canada, (n = 177,817), 92,276 received palliative care, and of those decedents, 84.9% received care in acute care hospitals. In England and Wales, the number of home deaths could decrease by 42% and fewer than 1 in 10 may die at home by 2030 (Gomes & Higginson, 2008). According to the authors, annual numbers of institutional deaths will be 530,409 by 2030 in England and Wales (currently it is 440,936, a 20% increase).

Moreover, in Canada, palliative care was known to be the main cause of hospitalization for more than half of all patients with cancer who died in acute care
settings (Fowler & Hammer, 2013). Those explanations further emphasized the significant role that hospitals play in the care of patients with advanced cancer and the delivery of palliative care. However, the great variances between countries in the place of death are only partially explained by differences in the cause of death, sociodemographic factors, and health care supply, which proposes that country-specific palliative and end-of-life care policies may be among the factors that play a vital role in where people die (Pivodic et al., 2016).

The Dearth of Cancer-related Palliative Care in Sri Lanka.

In the Asia Pacific and Oceania regions, Sri Lanka was identified as a developing country with limited provision of palliative care services to its populations (Lynch, Connor, & Clark, 2013). It was identified that only one clinic was available in Sri Lanka compared to Japan, which had 686. These authors mapped the world situation regarding palliative care in 2008 and 2013 and identified Sri Lanka as having localized provision and isolated provision, respectively (Lynch et al., 2013; Michael, Justin, Thomas, & David, 2008). Thus, palliative care in Sri Lanka is limited. Accordingly, there were no significant achievements in the field of palliative care in Sri Lanka from 2008 to 2013 (Lynch et al., 2013; Michael et al., 2008).

Hence, patients with life-threatening illnesses and patients with cancer who are in need of palliative care do not have access to it. According to the Palliative Care Association of Sri Lanka (2016), physical symptoms in cancer patients, as well as non-cancer palliative care patients, are usually addressed by the treating oncologist and the
respective physician as long as the patient is under his/her direct care. However, anesthetists are sometimes called to manage severe pain if the patient is admitted to a cancer hospital or any other relevant acute care setting (Palliative Care Association of Sri Lanka, 2016).

Furthermore, the Palliative Care Association of Sri Lanka (2016) highlighted that formal palliative care services are not yet available in Sri Lanka except for the few hospices that function as non-governmental organizations (NGOs) and offer incomplete services to patients with advanced cancer. The prominent NGOs are the Sri Lanka Cancer Society, Maharagama Shantha Sevana Home, Sri Lanka Palliative Care Organization, Northern Province Palliative Care Service, and Shanthi Foundation (Gunatilleke, 2019). Palliative care information and services can also be obtained from some public hospitals and units, such as Cancer Hospital, Maharagama (Apeksha Hospital), which is the setting for this study, National Cancer Control Programme, Palliative Care Unit and Maxillo-Facial Surgical Unit of the Kuliapitiya Base Hospital, and Palliative Care Unit of the Vavuniya General Hospital (Gunatilleke, 2019).

Hence, the Sri Lankan health system does not support the palliative care as a specialty, and it is practiced in only a few people in Sri Lanka and just a few oncology units in the public hospitals. There is only one cancer hospital in Maharagama, Sri Lanka, that must serve the entire population. However, the Ministry of Health, Nutrition, and Indigenous Medicine recently recognized that palliative care services in Sri Lanka need significant development and drafted the National Strategic Framework for Palliative Care Development in Sri Lanka for the period of 2018–2022 (Gunatilleke, 2019). The overall
goal of this framework is to promote quality of life, respect dignity and lifestyle, and ensure a holistic support system to patients with life-threatening illnesses and their families through evidence-based, multi-disciplinary, and cost-effective approaches. Further, eleven strategies were identified to achieve this goal. Among them, the seventh strategy is to “empower family members, caregivers for the provision of palliative care” (National Cancer Control Programme, 2018). Therefore, the proposed National Strategic Framework for Palliative Care Development in Sri Lanka has already identified the need for informal caregivers for the provision of palliative care.

The Bystander and Informal Care Provision

As there are no separate services for palliative care in Sri Lanka when people become seriously ill, they must be admitted to one of the general hospitals for treatment. Such hospitalized patients often face difficulties in fulfilling their self-care needs and, as a result, they need assistance (Quattrin et al., 2009). As nursing was founded on the notion of patient care traditionally as well as philosophically, these hospitalized patients with complex and intensive nursing care needs require nursing care around the clock (Cho & Kim, 2006). Even though the nursing staff in Sri Lanka assists patients in hospitals, due to heavy workloads and a shortage of staff members, their opportunity to provide caring is limited (De Silva & Rolls, 2010). Therefore, provision of help or care by in-hospital informal caregivers, known as bystanders, is a common phenomenon, particularly throughout the public hospitals.
In this study, the author used the word *bystander* to describe informal caregivers. B. F. Miller and Keane (1983), define an informal caregiver/bystander as “a lay individual who assumes responsibility for the physical and emotional needs of another who is incapable of self-care” (p. 256).

Further, a study conducted in Cyprus by Papastavrou, Charalambous, and Tsangari (2009) pointed out that the family has a vital role in maintaining the health status of their loved ones, and providing informal health care is critical in helping its members to manage with illness, as well as in assisting with the recovery and rehabilitation process. In research from India, when patients were admitted to the hospital for surgery, chemotherapy, or any other critically ill situation, their extended family and/or close friends who acted as bystanders were expected to be involved in bedside care of the patient during lengthy hospital visits (Chawak, Chittem, Butow, & Huilgol, 2019). Chawak et al. (2019) further point out that the quality of care provided by these bystanders is based on their educational level and any prior experience with cancer, including knowing someone with cancer.

Papastavrou et al. (2009) in Cyprus and Sapountzi-Krepi et al. (2008) in Greece further identify that patients who are admitted to hospitals need bystanders to provide assistance with personal hygiene, feeding, making beds, toileting, bathing, and helping take oral medication at the bedside. According to Chawak et al. (2019), the main reason for having informal in-hospital caregivers or bystanders in India is to encourage them to deliver in-hospital care to patients. It is further described as an amalgamation of a cultural caregiving tradition and an adaptation to the shortage of nursing staff in the hospital.
Amiresmaili and Emrani (2018) further highlight that, in Iran, hospitals that use the service of bystanders, either intentionally or unintentionally, can compensate for the lack of nurses to some extent and increase the satisfaction of patients and their families.

There is a similar situation in Sri Lanka, which has a severe shortage of nurses, and where the use of bystanders encourages the strong bond among family members (De Silva & Rolls, 2010). Watt et al. (2014) highlight that the family caregivers are strongly devoted to providing care to their parents who are aging or sick and express a sense of pride in the role they play as a caregiver. The commitment of family members to this kind of care has a basis in moral and religious obligation, societal expectations, and affection towards the patient, as has been highlighted in Sri Lanka. Further, Watt et al. (2014) state that Sri Lanka must be understood within the framework of Buddhism, where self-sacrifice and good moral conduct leads to spiritual enlightenment and positive karma (i.e., consequences in the current life and after-life).

The caregiving role in Sri Lanka is supported by people in the family and community, so caregiving is a shared responsibility that is consistent in other Asian settings (Watt et al., 2014). The authors further highlight that it is common to have a division of labor in providing caregiving to parents or loved ones; sons or sons-in-law normally provide financial support and daughters or daughters-in-law usually provide more direct caregiving. Smerglia, Miller, Sotnak, and Geiss (2007) showed that social support for the caregiver, and shared responsibility in caregiving, is important for caregivers’ well-being, and may, therefore, contribute to the sustainability of the caregiving role. Although there is no literature available, Sri Lankan public hospitals
have separate wards for males and females, in which bystanders must be the same gender as the patient. Therefore, daughters or daughters-in-law are not allowed to care for their fathers or loved ones who are males. This cultural norm sometimes creates situations when it is difficult to identify a bystander of the same gender.

The practical situation of bystander care has only been minimally described in the literature. Unofficially, family members are forced to stay with patients at their bedsides for many hours to assist with their care (Sapountzi-Krepia et al., 2008). According to De Silva and Rolls (2010), it was further evidence that the cancer hospital in Sri Lanka and its ward areas were congested and noisy, with many patients, bystanders, and health care workers, including doctors, nurses, and attendant staff workers, in the corridors, ward areas, and outdoor areas.

In conclusion, it is not only the patients who are admitted to the hospital who need assistance; health care workers also need help. Particularly, nurses expect assistance from bystanders for bedside care (Hui, Wenqin, & Yan, 2013; Sapountzi-Krepia et al., 2008).

**Types of Bystanders**

There are various types of bystanders involved in patient care as caregivers in different capacities in settings worldwide. Initially, caregivers can be classified as formal and informal (Claudia, 2003). Formal caregivers are professionals who are paid to deliver care, whereas informal caregivers are not paid. For example, a nurse can be considered a formal caregiver and a family member can be considered an informal caregiver (Claudia, 2003) or a bystander. The literature highlights *informal caregivers* to distinguish between
professional caregivers, such as nurses and other health care workers, and lay individuals, such as family members providing care because of pre-existing, interpersonal relationships with patients (Scherbring, 2002). Informal caregivers, who are known as bystanders in Sri Lanka, can include partners, close family members, or friends, and provide crucial support and play an important role inpatient care in a hospital, particularly for cancer patients along the illness trajectory (Romito, Goldzweig, Cormio, Hagedoorn, & Andersen, 2013). Thus, the informal label also implies the caregiver is unpaid.

Informal care provision is not limited to developing countries. According to Ambrosi et al. (2017), families in Italy play a significant role in the care of patients admitted to hospitals. They contribute to patients’ care, particularly during morning and afternoon shifts. Ambrosi et al. (2017) further pointed out that, when patients are at risk of lengthy hospitalizations or when they report adverse clinical events, such as pressure ulcers, falls, confusion, and the use of physical restraints, they are more likely to be in informal care in Italy. Most patients report that they prefer family caregivers because of the emotional support and comfort they provide (Cho & Kim, 2006). According to Waldrop (2006), in some families in the United States, caregiving was shared as shift-work in which those involved in primary care split the days or nights. The method by which nursing care is provided in China is slightly different from other countries (Hui et al., 2013) but similar to Sri Lanka; bedside nursing care is traditionally considered to be the responsibility of the family and nurses in public hospitals in Sri Lanka mainly carry out doctors’ orders, completing routine tasks oriented toward nursing and medical treatments (De Silva & Rolls, 2010, 2011).
According to Wohlschlagl (1991), as a result of the implementation of family planning policies, families have shrunk and family members find it difficult to be available for hospitalized patients. However, Waldrop (2006) pointed out that the division of caregiving tasks was related to the family’s economic situation, the number of family members, and their relationships with the patient. Further, a private aide was hired to provide hands-on assistance when a family caregiver could not provide full-time care (Waldrop, 2006). Hui et al. (2013) pointed out that, rather than being performed by a family member, the role of the bystander in hospitals in China has become an occupation for some who seek employment in the field of caring. Thus, caregiver services have slowly been established as private industries and are contracted by hospitals to provide a continuous supply of caregivers (Hui et al., 2013). Therefore, according to Hui et al. (2013), these two categories (hospitals and private agencies) have sometimes formed informal small-scale agencies within the hospital or close to the hospital. Based on my personal and professional observations in Sri Lanka, I can also note that there is no mention in the literature of the third type of bystander: trained or untrained people who offer paid bystander services independent of any agency or private group. However, there seems to be no available literature related to these two categories of caregivers (paid and unpaid) in Sri Lanka. Table 2.1 details this gap in the knowledge about types of bystanders, particularly the absence of data on paid bystanders. All of these types will be considered in the data analysis for this study. In addition, the data may indicate additional types not considered here.
### Table 2.1 Type of Caregivers in Sri Lanka and Their Basic Characteristics

<table>
<thead>
<tr>
<th>Types of Caregivers</th>
<th>Paid</th>
<th>Unpaid</th>
<th>Trained</th>
<th>Untrained</th>
<th>Previous experiences with caregiving</th>
<th>Limited Literature available</th>
</tr>
</thead>
<tbody>
<tr>
<td>Close family members/relations</td>
<td>-</td>
<td>√</td>
<td>-</td>
<td>√</td>
<td>+/-</td>
<td>√</td>
</tr>
<tr>
<td>Retired health care workers/attendants</td>
<td>√</td>
<td>-</td>
<td>√</td>
<td>-</td>
<td>√</td>
<td>-</td>
</tr>
<tr>
<td>People from the hospital environment</td>
<td>√</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>+/-</td>
<td>-</td>
</tr>
</tbody>
</table>

Therefore, research is needed on the three types of bystanders who provide informal care in hospitals in Sri Lanka; a) close relatives or friends who act as bystanders without payment on an involuntary basis; b) hired retired health care workers/attendants who act as bystanders, and c) hired people from the hospital environment or even from patients’ hometown/village. Given the lack of palliative care in Sri Lanka, a focus on bystanders’ provision of informal care to hospitalized cancer patients is especially needed.

**The Care Bystanders are Providing**

When patients are admitted to a hospital, they frequently face physical and mental challenges (Quattrin et al., 2009). They are in a critically ill and palliative care stage and under the influence of analgesics or other medications that can influence their ability to care for themselves and remember information (Kessels, 2003; Quattrin et al., 2009). Hence, they need assistance from someone; the bystanders’ role, therefore, attempts to
fill that gap. Many studies identified different bystander roles that address the overall care needs of the inpatient, particularly patients with cancer (Akpan-Idiok & Anarado, 2014; Amiresmaili & Emrani, 2018; Hassankhani, Eghtedar, Rahmani, Ebrahimi, & Whitehead, 2019; A. D. Miller et al., 2016; Stavrianou et al., 2018; Waldrop, 2006).

A. D. Miller et al. (2016) reported the qualitative findings from an interview and observation study of 48 people (28 patients and 20 caregivers) undergoing a multi-day stay in a hospital in the United States. It highlighted five roles that informal caregivers adopt: companion, assistant, representative, navigator, and planner. Further, caregivers coordinate communication with clinicians, care for patients’ overall well-being and activate wider networks of care in hospitals. The authors concluded that support for these important caregivers would enhance hospitalized patients’ care, potentially improving clinical outcomes, and even reducing medical errors.

A cross-sectional study by Stavrianou et al. (2018) identified the role of 210 informal caregivers in Greek hospitals during a family member hospitalization. According to the results, more than half of informal caregivers (58.1%, n=122) stayed by their patients’ bedsides for more than 17 hours per day. It was found that 13.8 patients were allocated to each nurse. Less than one-quarter of informal caregivers reported that their patients were not seriously ill at all. However, more than one-third of caregivers (35.7%, n=75) reported that their patient’s clinical status was extremely serious. Only 22.9% (n=48) of the patients were reported to be totally self-sufficient and able to take care of themselves. These informal caregivers mainly help the patient to take oral (28%) or rectal-administered medication (80%), change positions in bed (24%), complete their
morning toilet (face and teeth washing, hair combing) (7%), change nightgown/pajamas (12%), wash his/her hair in the bathroom (48%), and move with a wheelchair (50%); they sometimes help other patients hospitalized in the same room (25%). Further, caregivers were involved in blood glucose calculation and administration of insulin (71%), taking the patient’s temperature (52%), changing the urine bag (84%), administering the bed-pan (55%), providing massage (23%), encouraging the patient to perform his/her exercises provided by the physiotherapist (36%), watching the flow of the intravenous drip or blood (30%), making the bed (7%), changing bed linens (30%), preparing food/helping during eating/feeding the patient (17%), washing the patient’s hair in the bed (65%), getting the patient water or/and food from the canteen (16%), carrying plates to the kitchen (62%), carrying paperwork to the hospital offices (35%), and carrying blood samples and other samples to hospital labs (62%). The authors concluded that, given the lack of nurses, family members had to perform such basic nursing interventions to provide adequate and safe care and so they could participate in their family member’s care and provide further continuity of care at home.

Further research studied informal caregivers’ perceptions of the burden of caring for cancer patients at the University of Calabar Teaching Hospital, Nigeria. The research adopted a cross-sectioned descriptive design; 210 caregivers providing care to advanced cancer patients were selected (Akpan-Idiok & Anarado, 2014). The results highlighted the functional ability variables of care receivers; a scoring percentage of 50 and above indicated low functional ability when the care receiver (cancer patient) depended on a caregiver to help with performing activities of daily living, such as eating, showering,
dressing, using the toilet, dealing with incontinence, transferring from bed/chair/car, preparing meals, staying alone, supervision, managing money or finance, performing household responsibilities, and ensuring mobility. The study revealed that the majority, 137 (65.2%) of the care receivers had the low functional ability and depended heavily on informal caregivers.

The family caregiver role was further elaborated by Waldrop (2006) through a qualitative study to explore and describe the interrelationship between informal and formal care in terminal illness in the United States. In-depth interviews with 64 families highlighted that the primary relationship between terminally ill patients and those who were closest to them, such as spouses, adult children, siblings, or friends, most often evolved into caregiving relationships as the disease progressed. The study further showed that primary caregiving included increased numbers of hands-on tasks, such as assistance with toileting, bathing, and/or using a bedpan, as well as managing medical symptoms and end-of-life decision making. In some families, caregiving was shared as shiftwork, where those involved in primary care split the days or nights. In other families, the tasks of primary care were split: one primary caregiver would manage medications, and another would handle baths, bed changes, or medical tasks, such as catheter care. A private aide was hired to provide hands-on assistance when persons in primary relationships could not provide full-time care. However, in this study, the “caregiver shift” emphasized how multiple caregivers work together to accomplish complementary functions by forming shifting care configurations.
A qualitative study conducted by Hassankhani et al. (2019), explored the experiences of 21 Iranian family caregivers with regard to the burden of caregiving. Findings highlighted that family caregivers enter the caring role without any preparation, but they must provide 24-hour care for their patients. Becoming a family caregiver in the hospital leads to increased workload and decreased effectiveness in occupational and educational responsibilities. Further findings revealed that role conflicts (particularly balancing caring roles and family responsibilities) can lead to failure in professional or educational roles for informal caregivers. This emphasizes the need for culturally sensitive support based on family caregivers’ needs and circumstances.

Further, an Iranian study conducted by Amiresmaili and Emrani (2018) pointed out that using caregivers, either intentionally or unintentionally, in hospitals can compensate for the lack of health care workers (especially nurses) to some extent and increase patients’ and families’ satisfaction. They conducted a phenomenological study with 22 caregivers to explore the role of caregivers in the hospital. Findings highlighted the roles of caregivers, such as mental support security, helping the patient with all self-care and personal activities, facilitating physical recovery, and consulting for decision-making, participating treatments, and continuity of care. The authors concluded that using informal caregivers is an implicit strategy to overcome the nursing shortage and reduce hospital costs.

The inadequacy of nurse staffing is further highlighted in a Chinese research study that emphasizes how family-paid caregivers have been established as an important workforce for inpatient bedside nursing care in China (Hui et al., 2013). This descriptive
mixed-methods study combined qualitative interviews with a quantitative cross-sectional questionnaire survey. Six nurses were interviewed and 209 caregivers who were paid by families were surveyed. Results showed that patients relied heavily on these paid caregivers for assistance and care during hospitalization. The most frequently adopted task was feeding (mean 4.66, SD 0.95) and the least adopted task was taking oral swab specimens (mean 1.32, SD 0.97). In addition to feeding and help with daily hygiene (mean 4.49, SD 1.07) of patients, caregivers were commonly helpful with collecting urine or stool specimens (mean 4.35, SD 1.20) and administering medication to patients (mean 4.33, SD 1.29) after these medications had been delivered by nurses to caregivers. The authors concluded that the heavy workload of nurses and staffing inadequacy has led to a significant need for caregivers to provide bedside nursing care within hospitals in China. The authors further emphasized that the roles of paid caregivers need to be defined and closely monitored.

Bystanders have been described as the informal caregivers most directly involved with overall supportive care of patients. Whether the bystander is a family caregiver, or someone hired, the role of the bystander is complex and has many aspects. However, little is understood about the bystander role in the capacity of caregiver, coordinator of care with professional health workers, and advocate in Sri Lanka.

**Challenges Faced by Bystanders in Providing Care**

The significant involvement of bystanders in caring for patients admitted to hospitals can be seen in both developed and developing countries. Nevertheless, for a
significant number of patients, there are reports that document high levels of informal caregiving (Sadigh, Nawagi, & Sadigh, 2016). Previous studies pointed out the various challenges to appropriate caregiving among patients, especially in cancer-related palliative care (Muliira, Kizza, & Nakitende, 2019; Nemati, Rassouli, Ilkhani, & Baghestani, 2018). According to these risks, bystanders’ own comfort and well-being, the risk for neglecting and “lack of care” for their own children and families, the economic costs including lost time at work or the cost of paying for hiring a paid bystander and inadequate support from health professionals are major challenges especially faced by the unpaid bystanders in providing care.

A survey of 100 randomly selected informal caregivers was conducted in Mulago Hospital’s internal medicine wards to evaluate informal caregivers’ demographics, impact on patient care, and challenges (Sadigh et al., 2016). According to the results, 90% of informal caregivers stayed at Mulago for 11 days on average, with a range of 1-60 days. While staying at the hospital, 89% slept on the hospital floor. For meals, 29% obtained food from restaurants and 21% shared the patient’s hospital-provided meals. Further, 73% of informal caregivers reported that their work and/or school were affected by their time at the hospital. Accordingly, 25% put their jobs on hold, 21% left their farms or fishing jobs unattended, 18% suspended their businesses, and 3% left school. The open-ended questions with respect to caregiver challenges highlighted that 69% of informal caregiver families also felt affected. Hence, 35% of informal caregivers reported “lack of care” for their own children and families, 13% felt their family lacked financial support, 10% reported their family missed their presence at home, 7% reported family
concerns about upholding the cultural expectation that family members care for their ill loved ones as opposed to hired staff, 2% reported lack of childcare and finances, and 2% reported the inability to send their children to school. The authors concluded that informal caregivers make large sacrifices for their loved ones. They put aside their lives, families, children, school, and careers to care for their loved ones. They risk their own comfort and well-being tending to their loved one’s needs before their own, with consequences that may endure beyond the patient’s admission.

In addition, Nemati et al. (2018) conducted a qualitative study to explore challenges faced 21 by Iranian family caregivers of cancer patients through in-depth semi-structured interviews. The findings led to the emergence of four main themes, including ‘confusion’ due to lack of knowledge and feelings of inadequacy, ‘uncertainty’ due to the experience of being unstable and fearing the outcome of the disease, ‘disintegration’ due to helplessness and turmoil, and ‘setback’ due to exhaustion and caregiving tension. The authors concluded that the study participants saw themselves drowning in a sea of responsibilities; the ensuing difficulties tended to make them less efficient and, thus, exposed to the consequences of having conflicting roles that may also lead to economic problems.

Another qualitative study conducted by Hassankhani et al. (2019) in Iran explored the experiences of Iranian family caregivers with regard to the burden of caregiving. Interviews were conducted in the participants’ preferred locations, either in the hospital or outside the hospital. This was in the context of revealing and identifying the experiences of family members from different contextual perspectives. From the 25 semi-
structured interviews in total, four cases were used to highlight themes in the data.

Findings highlighted four categories and eight subcategories: burnout due to physical problems and psychological and emotional stress, role conflict due to balancing caring roles and family responsibilities and failure in professional or educational roles, health system tensions due to inadequate support from health professionals and ignorance of family members of the structure of health care, and social challenges of cancer due to economic burden and cultural taboos. The authors concluded that nurses need to provide individualized support and counseling to address these burdens. This study further highlighted the benefit of training health care professionals to provide culturally sensitive support based on family caregivers’ needs and circumstances. This seems to be the only study that focuses on the potentially supportive role of nurses in facilitating bystanders’ provision of informal care.

Caregiver challenges were further elaborated in a sub-Saharan country through a cross-sectional descriptive study that was used to collect data from 168 family caregivers (FCG) of hospitalized adult cancer patients (ACP) to explore the tasks performed and the caregiver burden experienced by FCGs of hospitalized ACPs (Muliira et al., 2019). In this study, the Caregiver Burden Scale, which was originally used to measure caregiver burden for stroke patients and was later adapted to reliably measure caregiver burden in cancer patients, was used to measure caregiver burden. The main predictors of overall perceived caregiver burden were the FCGs’ level of education (P=.018), ACPs’ length of stay in the hospital (P=.031), and the requirement to give medications to ACPs (P=.049). The most significant predictors were identified as a disappointment, emotional
involvement, and environmental burden. The predictors of disappointment were FCGs’ level of education (P=.003), the number of people cared for (P=.028), and relationship with the patient (P=.040). The key predictors of emotional involvement were FCG marital status (P=.004) and ACP complaints of general weakness (P=.003). The main predictors of environmental burden were the care activities of making meals (P=.009), washing and body hygiene, ACP complaint of pain (P=.029), and the FCG relationship with the ACP (P=.029). Hence, the authors further pointed out that the process of caregiving and the roles and tasks performed by FCGs lead them to experience challenges of severe general strain, disappointment, and isolation.

The challenges faced by the bystanders in providing care were identified in many studies conducted in both developed and developing countries. Sacrificing their own comfort and well-being, these caregivers look after hospitalized patients, including patients with cancer. Sometimes they had to sleep on the floor and share food with patients. Due to the need to stay in the hospital with their patients, these caregivers’ families, children, and livelihoods were also affected. Lack of finances, lack of proper education in caring, severe general strain, disappointment, isolation, and health system tensions due to inadequate support from health professionals were the major challenges that the research has detailed, emphasizing multiple burdens faced by informal caregivers.
Type of Interactions and Communication with Nurses and Bystanders

Some of the studies described above also addressed the type of interactions and communication between bystanders/informal caregivers and nurses (Amiresmaili & Emrani, 2018; Hassankhani et al., 2019; Hengelaar et al., 2018; Hui et al., 2013; Muliira et al., 2019). According to these authors, there are multiple difficulties regarding these interactions and communications, including a clear deficit in bystanders’ attitudes in caring related to inadequate education, inaccurate knowledge, low skills for appropriate caring procedures, and poor acceptance by health care workers, including nurses. However, in spite of these reported deficits, bystanders continue to be encouraged and even required to provide patients with bedside care in hospitals.

A thematic synthesis of 22 articles from Canada (10/22), Europe (5/22), the United States (2/22), Australia (2/22), New Zealand (1/22), Israel (1/22), and South Africa (1/22) sought to examine and understand how professionals experience collaboration with informal caregivers to strengthen the care triad, a care network consisting of a client, informal caregiver, and health care professional/nurse (Hengelaar et al., 2018). The study findings highlighted that nurses/professionals use their own knowledge, status, and authority to achieve the tasks of practice in patient care and their set professional mandates while giving little acknowledgment of the knowledge, status, and authority of informal caregivers as potential partners in care. Therefore, nurses were not always working in partnership with informal caregivers, given the scant number of meetings between the two groups. When considering communication between professionals and informal caregivers, it was only described in terms of difficulties,
including insufficient and irregular communication; no best practices were mentioned in these countries. The study findings concluded that working in collaboration with informal caregivers requires professionals/nurses to adopt a different way of functioning, such as educating informal caregivers appropriately about the need for care. Specific attention should be paid to informal caregivers; the focus now is mainly on the client for whom they care.

This situation was further highlighted by a qualitative study by Hassankhani et al. (2019) exploring the experiences of Iranian family caregivers. Family caregivers stated that nurses excluded them from participation in patient care and did not consider their needs as caregivers. In some instances, they were sent out of the hospital room when the doctor visited the patient, and limited mechanisms were in place for caregivers to communicate with doctors and nurses and receive support. Hence, this study noted an overall ignoring of caregivers by nurses and doctors. However, the researchers further highlighted that the high workload of doctors and nurses can lead to family caregivers being ignored.

Although many informal caregivers report being ignored by the nurses, it has been shown that informal caregivers do have importance for nurses. This was highlighted by Hui et al. (2013), who examined the role of caregivers in hospital bedside nursing care in China. Due to nurses’ workload being consumed by providing medical treatments and documenting care, nurses warmly welcomed informal caregivers to the ward; these informal caregivers were accessed often by nurses. If caregivers requested help, nurses would work with them to provide the needed care. For nursing care that required medical
knowledge and specialized nursing knowledge and skills, the hospital had special guidelines that would limit the role of the caregivers. Therefore, this study concluded that informal caregivers play a significant role in patient bedside care and nurses continue to rely on them for varying degrees of inpatient care.

Further communication and effective interaction with nurses and nursing care were highlighted by a cross-sectional descriptive study of 168 family caregivers of adult cancer patients. The study explored the tasks performed and caregiver burden experienced by family caregivers of hospitalized adult cancer patients in a sub-Saharan country (Muliira et al., 2019). The results indicated that, in low-income settings, informal caregivers have the additional burden of carrying out nursing-oriented care such as feeding, giving medications, and other tasks due to the severe shortage of nurses. This extra burden seems to originate from needing to perform tasks that are part of the practice of professional nursing. According to the authors, this may indicate that, in low-income settings, family caregivers are bridging the gaps in cancer care and the health care system by providing care that should otherwise be nurses’ responsibility. However, the study concluded that the wide-ranging involvement of informal family caregivers in the performance of unfamiliar and sometimes professional-level nursing-related tasks causes severe strain, isolation, and disappointment.

Further, the Iranian study conducted by Amiresmaili and Emrani (2018) found that informal caregivers interact with nurses throughout the caring process. Due to their low information and low literacy, they try to do some patient-related activities that should be performed by nurses. This sometimes creates conflicts between informal caregivers
and nurses. Informal caregivers further had high expectations that nurses would always attend to their patients. Due to the shortage of nurses and their huge workload, nurses may not always be able to fulfill their expectations, which creates a problematic relationship between nurses and informal caregivers. However, this study further pointed out that, although there are strengths and weaknesses to having informal caregivers in the hospital, it helps to fill the gap created by the shortage of nurses and provides continuity of care with the limited number of nurses, providing overall higher satisfaction for patients.

Overall it can be concluded that, although bystanders/informal caregivers sometimes have been ignored by nurses, or may experience conflicts with nurses, nurses need them to fill the care gap due to the severe nursing shortage, particularly in developing counties. Evidence currently available highlights that interactions and communication between nurses and bystanders are insufficient, irregular, and characterized by conflict or coordination, and there exist no best practices to build effective collaboration between nurses and informal caregivers and enhance informal caregiver practice within the hospital. None of the available research describes the features of communication between nurses and bystanders in Sri Lanka.

**Recommendations of Bystanders to Improve Informal Care**

Given the current severe shortage of nurses, especially in developing countries, nurses find it difficult to deliver comprehensive care without using bystanders as informal caregivers (Hui et al., 2013; Muliira et al., 2019). Therefore, many studies recommended
improving the practice of bystanders/informal caregivers for bedridden patients in hospitals.

A qualitative study of Iranian family caregivers (Hassankhani et al., 2019) highlighted that caregivers need formal and comprehensive training about caregiving, adequate assistance from nurses for caregiving, adequate space to rest or to stay overnight with patients, and appropriate acceptance within the health structure. These informal caregivers say that they need full support from health systems to provide care to family members living with cancer in the hospital.

The study by Hui et al. (2013) in China reported that nurses depend on the caregivers for bedside nursing care and that caregivers’ roles need to be clearly defined and closely monitored by the nurses. Further, the appropriate management of caregivers’ roles and improved nurse supervision were required to ensure the quality and safety of patient care. The authors concluded that the nursing workforce needs to be restructured in response to the changing needs and expectations of patients and their informal caregivers.

Muliira et al. (2019) elaborated on the need for oncology nurses to care for advanced cancer patients in a sub-Saharan country and to support and educate family caregivers, especially in low-income settings with a high prevalence of cancer. Interventions that can be further implemented by oncology nurses to improve the well-being of family caregivers include psychotherapy and group therapy to increase self-esteem and coping skills, psychoeducation skills training to encourage confidence and self-efficacy, family meetings to offer a safe setting to process emotions, respite care to reduce burnout, and palliative and hospice care to help healthy bereavement. Therefore,
according to the authors, one of the strategies needed to improve cancer care for inpatients in low-income settings is a repositioning to view caregivers and cancer patients as one unit. This unit requires holistic care and streamlining of human resources to ensure the availability of an adequate number of trained oncology nurses.

Bystanders/informal caregivers not only highlighted the support of the nursing workforce but also recommended improving facilities to enhance their stay in the hospital with their patients. This was emphasized by Amiresmaili and Emrani (2018) in Iran. Informal caregivers reported not having enough space or adequate facilities or training to stay with patients at the hospital. They had no facilities for food, drinking water, toilets, or buffets; they lacked proper training and support from nurses to develop their knowledge and skills in caring for patients. Therefore, the authors highlighted that informal caregivers need overall basic facilities within the hospital and adequate training to develop the knowledge, attitudes, and relevant skills necessary for basic caring activities related to their patients.

Bystanders pointed out that they need proper training, guidance, and supervision from nurses or relevant authorities to perform their tasks effectively, as well as the infrastructure and facilities to provide adequate informal care. Overall, they expect proper recognition as informal caregivers/bystanders and support for the care they are providing to their patients.
Social-ecological Model: A Conceptual Framework for the Study

A conceptual framework that speaks directly to behaviors and their individuals, as well as environmental determinants, is known as an ecological perspective (Bronfenbrenner, 1979). Following variations of the Bronfenbrenner model, McLeroy, Bibeau, Steckler, and Glanz (1988) are generally credited with creating the social-ecological model of care. In the social-ecological model, human health and health care choices are identified as being affected by multifaceted levels of influence (K. R. McLeroy et al., 1988). Further, theories or models based on social-ecological perspectives are important and relevant because they encourage a comprehensive understanding of the multifaceted levels of influence on cancer-related health care.

Ecological concepts have a significant influence on various disciplines, including sociology, psychology, public health, and education. The word *ecology* is derived from biological science and refers to the interrelations between organisms and their environments (Daniel Stokols, 1992), and *ecological* refers to models, frameworks, or perspectives (Sallis & Owen, 2002). Further, the social-ecological perspective is based on not one singular discipline or theory, but also on a broad paradigm that connects several fields of research for understanding the relationships among diverse personal, social contextual, and environmental factors in human health and illness (D. Stokols, 1996). Social ecology gives greater attention to the social, institutional, and cultural contexts of people, environment relations or transactions, and the impact of the relations or transactions on human wellness (Daniel Stokols, 1992; D. Stokols, 1996).
This model is focused on patterned behavior that is the outcome of interest; behavior is viewed as being determined by five steps, including individual intrapersonal factors, interpersonal process, and primary groups, institutional factors, community factors, and public policy (K. R. McLeroy et al., 1988). Hence, it is of paramount importance to use model levels to reflect the range of strategies for interventions to promote public well-being within a community and a particular social environment (D. Stokols, 1996), which in this case is a cancer setting in Sri Lanka.

Bystanders have to engage in the society of cancer hospitals in Sri Lanka, which have their own cultural values, beliefs, customs, and social norms. As health-related phenomena are not only affected by individual factors but also broader cultural, social, and contextual factors, there is a need to consider the influence of multiple societal levels and their interrelationships across all levels. Hence, this more comprehensive approach to the social-ecological model can enable a better understanding of factors influencing health-related choices and the interactive effects between levels (K. R. McLeroy et al., 1988). Appropriate strategies that are reflected at each societal level help to explore the role of bystanders who looks after bedridden patients with cancer in Sri Lanka (Figure 2.1).
Figure 2.1 A Social-ecological Model: A Conceptual Framework for the Study that
Adapted from McLeroy, Bibeau, Steckler, and Glanz (1988).
**Intrapersonal Factors**

The intrapersonal factor that is the first level of this model is the most specific factor that influences the role of the bystander. For this study, it was assumed that individual characteristics of bystanders that influence patients’ care include personal attributes, knowledge, and attitudes about caring and skills/training related to the caring process. The literature suggests that individual characteristics that promote or undermine health and health-related activities include knowledge, attitudes (K. R. McLeary et al., 1988), beliefs, personality traits, psychological and biogenetic factors (Daniel Stokols, 1992; D. Stokols, 1996), socioeconomic status, educational level, and employment status (Fleury & Lee, 2006). These intrapersonal attributes of bystanders can also influence the well-being of cancer patients or bystanders themselves, either directly or in conjunction with a variety of social and contextual circumstances (D. Stokols, 1996). Apart from these intrapersonal attributes of bystanders, there are various types of bystanders in the cancer setting in Sri Lanka, such as paid-unpaid, trained-untrained, and close relative or family friend at any education level and any age level.

**Interpersonal Factors**

Interpersonal processes refer to the influence of formal and informal social networks and social support systems, including family members, friends, and other networks, on health and health-related personnel (K. R. McLeary et al., 1988). At the interpersonal level in one study, primary groups of social interactions, including family, partner, and friends, were considered. Family processes or family interactions are
frequently involved in the day-to-day production of health through such activities as supporting or modeling lifestyles (Grzywacz & Fuqua, 2000). The authors further highlighted that a higher level of emotional involvement among family members, a lower level of interfamily conflict, and more effective forms of communication and problem solving have been found to promote public wellness and healthy lifestyles. The present study hypothesized that individual preferences for informal caring are influenced by close ties with family, partners, or friends, and social interactions in a social network that an individual can rely on to offer emotional, information, or physical or material support in relation to informal caregiving. Bystanders also learn how to deliver informal care by observing others’ experiences within a social network at the end of life. The literature suggests that individual health-related factors are often influenced by the attitudes and actions of families and informal social networks with which an individual interacts in the social environment where they live and where their growth occurs (Kenneth R. McLeRoy, Norton, Kegler, Burdine, & Sumaya, 2003). McLeRoy et al. (2003). In addition, the literature shows that individual characteristics can affect the social networks to which bystanders have access in the clinical setting of this study. An individual’s social networks are also largely developed within the context of the hospital community and social environments that bring people into contact with other bystanders and health care workers (McLeRoy et al., 2003).
Institutional Factors

A third level of the social-ecological model is the organizational or institutional level. According to McLeory et al. (1988), institutional/organizational characteristics can be directly influenced by workers and clients. It is further used to support behavioral changes in the people who are part of the organization. Hence, for bystanders, this study was highly influenced by the organization. Bystanders need to adhere to the organization’s formal and informal rules and regulations (K. R. McLeroy et al., 1988). As bystanders are not directly related to the workforce of this study organization, which is a cancer hospital in Sri Lanka, they mainly need to respect the hospital’s general common rules and regulations. Although there are many bystanders in the cancer hospital, there is no legal framework to protect them or their patients; we will explore this through this study. Management styles, lack of participation by workers, poor relationships with supervisors, and communication problems will also be considered social worksite hazards (K. R. McLeroy et al., 1988), which this study also explored.

Community Factors

Community is known as the mediating structures or face-to-face primary groups to which an individual belongs. This view embraces informal social networks, neighborhoods, churches, and voluntary organizations (K. R. McLeory et al., 1988). McLeory et al. (1988) further suggested that mediating structures can be important sources of social resources and are important influences on the larger communities’ norms and values, individual beliefs, and a variety of health-related choices that will
support the bystanders in this study. They can also serve as connections between individuals and the larger social environment (McLeory et al., 1988) in this cancer hospital. This assumes that resource support for planning informal caregiving could be from primary groups in their communities to which individuals belonged, including neighborhoods, community centers, voluntary organizations, churches, and health services. It was also assumed that such resource support could influence their views and preferences for care provided at the bedside for bedridden cancer patients. It has been proposed that, in the community, resources may take a variety of forms, including people who possess knowledge and skills, as well as settings that can provide venues for interaction (McLaren & Hawe, 2005). Therefore, it is important to focus not only on the interrelatedness of the practice of caregiving within single settings, such as one patient or one ward but also on the links between multiple settings and caregiver practice within the broader community (Daniel Stokols, 1992; D. Stokols, 1996). This helped to highlight the broader role of the bystander in this study.

**Public Policy**

The use of regulatory public policies, procedures, and laws helps to protect the health of the community (K. R. McLeroy et al., 1988). Laws and policies need to be standardized to ensure proper practice in health care, especially related to caregiving. In Canada, policymakers have shifted their attention to finding ways to support and empower informal groups of helpers and caregivers as part of a strategy to avoid or delay the institutionalization of patients, and as part of a trend toward helping people stay in
their own homes and communities (Khayatzadeh-Mahani & Leslie, 2018). However, there is no single policy for informal caregiver practice in Sri Lanka. This study explored the importance of introducing relevant policies for informal caregivers/bystanders through this social-ecological model.

Overall, this model helped show the different levels of responsibilities of bystanders. The goal of the study was not only to explore each of the layers but also guided data analysis.

**Summary of the Literature**

This literature review shows that there is no separate specialty called *palliative care* in the Sri Lankan health system; therefore, it has limited and incomplete use within the hospital setting. People who become seriously ill need to be admitted to public hospitals for treatment. In many hospital settings, it is not only the admitted patients who need assistance; due to the severe shortage of health care workers, particularly nurses, assistance from the patient’s family in the form of bystanders to provide bedside care is often an expectation. Further, the cultural family bonds in developing countries like Sri Lanka may also be another reason to keep an informal caregiver to provide in-hospital care.

This review further highlighted that bystanders make significant sacrifices for their patients; they set aside their lives, families, and even their children. The economic burden, lack of proper education for caring, severe general strain, disappointment, isolation, and health system pressures due to inadequate support from health
professionals were the major challenges faced by informal caregivers. Even given these challenges, as well as lack of recognition for the role of informal caregivers in the existing health systems in many countries, it is impossible to fulfill individual caring needs without these informal caregivers, particularly in developing countries experiencing a severe nursing shortage. However, the interactions and communication between nurses and bystanders were recognized as insufficient and irregular, and no best practices have been developed to ensure effective collaboration between nurses and informal caregivers, which would enhance informal caregiver practice within the hospital. Therefore, these informal caregivers asked that their role in the health system receives proper recognition and that hospitals provide enough basic facilities so that they can stay with patients and provide adequate informal care.

A social-ecological model was used as the conceptual framework guiding data analysis for this study. This model helped to identify the ecological layers of bystanders’ different care tasks, interactions within and outside of the hospital ward and possible policy supports for their responsibilities. Overall, the review identified that bystanders/informal caregivers are needed in the current clinical setting, especially in developing countries and for hospital-based cancer patients. Therefore, bystanders’ perspective on the provision of care is vital to understand and recognize their role, which will help to enhance their practice toward comprehensive care for hospital-based bedridden cancer-related palliative care patients.
CHAPTER 3
METHODOLOGY

This chapter describes the methodology and research design of the study of bystanders’ perspectives on the provision of informal, hospital-based care to bedridden cancer patients in Sri Lanka. Specifically, the rationale for selecting qualitative research as the methodology for the study is presented. The qualitative descriptive design will be detailed, as the data collection strategy of semi-structured interviews. This chapter also identifies this study’s setting, sampling, recruitment, human subject protection, data sources and collection, data analysis, and strategies used to ensure the study rigor.

Qualitative Descriptive Design

Qualitative nursing research emerged from the methodologies of several different social science disciplinary traditions (Morse & Field, 1995). However, the qualitative approaches derived from other disciplines have not always met the unique demands of nurse researchers (Thorne, Kirkham, & MacDonald-Emes, 1997). Thorne et al. (1997) and Sandelowski (2000) considered non-categorical qualitative research approaches that were derived from an understanding of nursing’s philosophical and theoretical foundations as reliable and appropriate ways to access knowledge for nursing. In this context, the qualitative description is especially amenable for nursing research because it can identify the features of a phenomenon and discover and understand a phenomenon, a process, or the perspectives and worldviews of the people involved (Caelli, Ray, & Mill, 2003; Denise F Polit & Beck, 2009).
Qualitative descriptive design is an empirical method of investigation aiming to describe the participant's perception and experience of the lived world and its phenomena (Neergaard, Olesen, Andersen, & Sondergaard, 2009). The essence of qualitative description lies not only in the knowledge it can produce but also as a vehicle for offering and treating research participants as living entities that resist simple classification (Sandelowski, 2010). The qualitative description designs as advocated by Sandelowski (2000, 2010) are an exceptional methodological choice for the designer, practitioner, or researcher of health care settings as they provide rich descriptive content on health and health care from the participants’ perspective.

A qualitative descriptive approach should be the design of choice when a straightforward description of a phenomenon is desired (Neergaard et al., 2009; Sullivan-Bolyai, Bova, & Harper, 2005). It is useful when researchers want to know, regarding a particular phenomenon, who was involved, what was involved, and what activities took place. Therefore, the research question, “What are bystanders’ perspectives on the provision of informal, hospital-based care to bedridden patients with cancer in Sri Lanka?” fits well with the descriptive qualitative research design.

According to Neergaard et al. (2009), the aim of descriptive qualitative research is neither detailed description, such as ethnography, nor theory development, such as grounded theory, nor identifying the essence of an experience (phenomenology), but rather a rich, straightforward description of a phenomenon. This means that, in the analytical process and presentation of data, descriptive qualitative research design stays close to the data. Thus, the final product of descriptive qualitative research in this study is
a description of bystanders’ care for hospitalized bedridden cancer patients in Sri Lanka, including types of care activities and communication with nurses, patients, and other relevant health care workers in a language like the participants' own language (Neergaard et al., 2009; Sullivan-Bolyai et al., 2005).

A qualitative descriptive approach is possibly the least theoretical of the qualitative approaches (Neergaard et al., 2009) and the least burdened by pre-existing theoretical and philosophical commitments (Sandelowski, 2000). In relation to this study, the research built upon existing knowledge related to bystanders and their role in inpatient care in the hospital and included thoughtful linkages to the work of others who have examined informal caregivers and their roles and experiences.

According to Sandelowski (2000), the data collection in qualitative descriptive studies is naturally focused on discovering the who, what, and where of events or experiences. Data collection techniques usually consist of minimally to moderately structured open-ended individual and/or focus group interviews, observations of targeted events, and the examination of documents and artifacts (Sandelowski, 2000; Sullivan-Bolyai et al., 2005).

Sandelowski (2000) takes a literal or objective view of qualitative descriptive data analysis, assuming that “simple straightforward description” of “events or experiences” does not contain participants’ interpretations of those events or experiences. For Sandelowski, qualitative content analysis is the data analysis strategy of choice in qualitative descriptive studies. Content analysis refers to a technique commonly used in qualitative research to analyze words or phrases in text documents (Sandelowski, 2000).
In this study, content analysis was conducted to identify types of care, ranking the most commonly mentioned to the least commonly mentioned.

In contrast, Colorafi and Evans (2016) and Thorne et al. (1997) insist that even descriptive qualitative data has an interpretive dimension. In the past, some qualitative nurse researchers justified their abandonment or avoidance of a theoretical foundation with the claim that “nothing is known” about certain disease experiences (Thorne et al., 1997). However, in arguing for the need for an interpretive description, Thorne et al. (1997) suggested that what is known, whether by virtue of formal research or experience, should be considered to be the foundational fore structure to any new inquiry. Further, according to Clancy (2013), the advantage of an interpretive qualitative description approach is that data analysis is more likely to remain true to participants’ accounts and contribute to ensuring the transparency of researchers’ own interpretations.

Nevertheless, both content analysis and thematic analyses can be used with good effect in the analysis of data from qualitative descriptive studies (Bradshaw, Atkinson, & Doody, 2017; Thorne et al., 1997). As noted by Vaismoradi, Turunen, and Bondas (2013), quantification of the data is more likely with content analysis, which may fit better with the “straight description” of the data associated with qualitative descriptive designs or with particular research questions aiming to describe the particular features or aspects of a phenomenon (such as the types of activities conducted by a bystander). Although the emphasis is placed on description, analysis of qualitative description data will involve some interpretation, such as that required in the thematic analysis (Sandelowski, 2000; Thorne et al., 1997). Further, according to Thorne et al. (1997),
interpretive description in nursing demands that nurse researchers come to know individual participants’ data closely, abstract relevant common themes from within and across individual participants’ data, and help to produce knowledge that will itself be applied back to the research participants or their community, which is one of the significant outcomes of this study. Thus, this study used a combination of content analysis and thematic analysis methods.

The Study Evolution

This study emerged from my professional and educational background and experiences in the field of palliative care. I began my profession as a registered nurse in Sri Lanka after finishing three years of General Nursing Diploma education at the Nursing Training School (NTS) in Colombo. As a registered nurse, I served as a neurosurgical nurse for six years, then I was promoted to nurse manager/ward master in the urological unit at National Hospital in Sri Lanka, after completing a one and half year Post Basic Nursing Diploma in Ward Management and Supervision. Furthermore, I completed my tertiary education qualifications, including a Diploma in Psychological Counseling, Bachelor of Nursing, and Master of Nursing, during which I focused on nurses’ cancer pain management in Sri Lanka.

While I worked as a registered nurse at the National Hospital of Sri Lanka, I participated in a project funded by the British Council to establish cancer pain treatment facilities in Sri Lanka; this was a collaborative project with a United Kingdom cancer pain center (Williams, Chandler, Ranwala, De Silva, & Amarasinghe, 2001). The project
focused on establishing the first cancer pain clinic in the Cancer Hospital/Apeksha Hospital in Sri Lanka. Based on the knowledge and skills gained from that project, I conducted a small quantitative research study by collecting data from 100 nurses exploring their awareness about pain management. The findings of the study were published in the Journal of Pain and Symptom Management, a journal based in the United States (Williams et al., 2001). This initial research study increased my interest in this area of study. Subsequently, I explored the nurses’ cancer pain management practices in the Cancer Hospital/Apeksha Hospital in Sri Lanka in 2009 as a qualitative ethnography study to partially fulfill requirements for my Master of Nursing degree from Australian Catholic University in Melbourne; this study was published in the Journal of Nursing and Health Sciences (De Silva & Rolls, 2010, 2011).

In addition to my existing background as a qualitative nursing researcher and my previous exposure to cancer palliative care, my own experiences being a bystander also deeply influenced this study evolution. In 1997, I served as a bystander for my own father who was diagnosed with unknown primary cancer that had metastasized throughout his body. He was admitted to the same cancer hospital for chemotherapy and radiotherapy after the removal of lymph nodes in his groin area. While I was working as a nurse at the National Hospital of Sri Lanka, I would stay with my father as much as possible as a bystander. Due to congested wards and a severe shortage of nurses, I had to engage with my father’s personal care as he gradually became bedridden and needed personal assistance. Being a bystander, I stayed at my father’s bedside. I had only a plastic chair close to the bed and had to use the ward’s limited common facilities, such as common
bathrooms and showers. The ward was quite different from contemporary United States in-patient units which typically have one or two beds per room; the ward in which my father was placed resembled a large hall and had approximately 50 beds, in addition to 80 or 90 patients who were on the floor area due to the limited number of beds. Being a bystander without basic facilities and not much recognition or communication from the nurses and doctors was a difficult situation. It was made worse due to my father experiencing the end-of-life stage. I will never forget my own physical and emotional experiences of being a bystander for my father, who passed away three months after his diagnosis. This gave me more insight into this study and helped me to understand the bystander role.

Both my personal experience of being a bystander and my academic background as a qualitative nursing researcher in cancer palliative care helped me to see that having bystanders care for hospitalized bedridden patients with cancer is unavoidable due to the severe shortage of nurses and a large number of patients (De Silva & Rolls, 2010). Therefore, I decided to examine the role of bystanders for patients with cancer, which I had noticed was a neglected area of health research in Sri Lanka and many other countries. Further, these previous experiences helped me to develop a rapport with bystanders in the field. It also helped me to feel comfortable within the hospital community setting. Since I had not been involved in cancer nursing, it provided me the ability to ask questions regarding the bystander role, with special reference to the nurse-bystander relationship. “Knowing too much can foreclose in-depth conversations; knowing too little can appear rude and uninterested” (O'Reilly, 2005, p. 90).
Further, this previous exposure helped me identify strategies to develop a palliative care approach by identifying the importance of the bystander role in the Sri Lankan context. There are palliative care models in many countries. However, questions exist about whether those models fit into the Sri Lankan context, which needs to be researched.

**Researcher Bias**

In qualitative research, the researcher is also an instrument of the research project and, therefore, is a participant (Denzin & Lincoln, 2008). The researcher as an instrument needs to constantly reflect on the cyclic process of data collection and data analysis to direct the research study and obtain insight into the phenomenon they wish to study (Carolan, 2003; Crotty, 1998).

Qualitative approaches have a connection with the subjective nature of social reality and provide insights from the participant's perspective. The issue that I as a researcher faced with this study was my previous experience of being a bystander for my father in the same cancer hospital. Further, I studied cancer pain management in this hospital setting for my Master of Nursing degree and published two articles exploring the health care system and nursing in Sri Lanka and attitudes, beliefs, and practices of Sri Lankan nurses toward cancer pain management (De Silva & Rolls, 2010, 2011). Therefore, as the researcher, I could be considered an insider. Being an insider (emic perspective) helped me to examine the experiences, feelings, perceptions, and practices of bystanders and the ways in which they interpret events. An outsiders’ view of the world
of informal caregiving, (etic perspective) does not enable such understanding easily (Denise F. Polit & Beck, 2006, 2008). An insider perspective helped me engage with the bystanders and established rapport without the notion of being a foreigner in their field (Roper & Shapiar, 2000).

Study Setting

The study took place in Sri Lanka, which is a small island in the Indian Ocean situated at the southern tip of India. The landmass comprises 65,610 square kilometers. There are also many smaller islands around the country (Department of Census and Statistics-Sri Lanka, 2018). Sri Lanka is similar in size to Ireland (Williams et al., 2001) but has a much larger population at 20.6 million (Department of Census and Statistics-Sri Lanka, 2018).

The study was set in Colombo, the capital city and financial center of Sri Lanka. The city has a population of 752,993. The larger urban area has a population of more than 2.3 million, while the metropolitan area has a population of more than 5.6 million (Department of Census and Statistics-Sri Lanka, 2018; World Population Review, 2019). Cancer treatment is provided at the National Cancer Institute, which is also known as Cancer Hospital and Apeksha Hospital, in Maharagama, a Colombo suburb. Maharagama’s population is 208,802 (Divisional Secretariat - Maharagama, 2019). Many bystanders stay in the hospital full time at their patients’ bedside; few of them stay temporarily in affordable lodging in Maharagama while providing informal care to hospitalized cancer patients. Bystanders who travel from distant places in Sri Lanka may
have no relatives or friends in Colombo who can support them (The Island, 2013). In fact, for some, it is their first visit to Colombo. There are also community-based offices and informal street locations where bystanders can be hired. Recruiting took place in the cancer hospital wards where the bystanders look after their patients. Nearly all bedridden patients have bystanders due to the severe shortage of nurses and other supportive health care workers, which creates chaotic situations in many wards in the cancer hospital (De Silva & Rolls, 2010, 2011).

**Sampling**

It is important that the sampling methods selected for a research study reflect the research design and the research questions (Bradshaw et al., 2017). Accordingly, Parahoo (2014) believes the sampling procedure that is compatible with a qualitative description design is a nonprobability technique of convenience or purposive sampling method. Kim, Sefcik, and Bradway (2017) note that most qualitative descriptive studies use a purposive sampling method. Purposive sampling is appropriate as it enables the researcher to access participants who are especially knowledgeable of the research topics (Neuman, 2006). Bradshaw et al. (2017) further showed that purposive sampling offers the additional benefit of enabling the selection of participants whose qualities or experiences can inform the study. As the types of informal caregivers can include family members, relations, friends, and paid caregivers, both trained and untrained, maximum variation sampling that consists of the selection of participants likely to reflect different perspectives is preferred (Creswell, 2013). Initially purposeful sampling was planned for this study, but
due to the COVID-19 pandemic, the researcher changed to snowball sampling. Snowball sampling as a purposeful method of data collection in qualitative research is applied when samples with the target characteristics are not easily accessible (Creswell, 2013).

**Study Sample**

Therefore, using purposeful and maximum variation snowball sampling, the study sample consisted of 17 participants who met the inclusion criteria: adults ages 21 or older with at least one month of experience in the past 12 months as a bystander/informal caregiver for hospitalized cancer patients in Sri Lanka. Even though the initial plan was to recruit 20 participants, after 17 participants were recruited and their data analysed, saturation was reached. Therefore, the total sample consisted of 17 participants. The sample was aimed to include paid, unpaid, trained, and untrained bystanders and included both men and women. Bystanders who belonged to religious minorities (e.g., Muslim, Hindu, and Christian) were also included in the sample. Therefore, purposeful and maximum variation snowball sampling of bystanders informed a diverse sample with various personal perspectives regarding the role of bystanders. Due to the nature of snowballing sample some bystanders who did not fulfill some inclusion criteria were also contacted by the researcher via the telephone. However, if the bystanders did not fulfill any inclusion criteria, they were excluded from the study after the screening conversation; appreciation for their willingness to participate to the study was communicated to these individuals.
Recruitment

Participant recruitment occurred in the cancer hospital at Maharagama. Most of the bystanders are used to staying in the same ward as the patient. During the day, they use a chair to sit closer to the patient and at night, they sleep close to the bed on the floor or even on the chair, lying their head on the bed. Some bystanders, who come from all over the country, try to stay in Maharagama at places such as temples, transit homes maintained by charities, and various other types of lodging since they may not have relatives or friends living in Colombo with whom they can stay while serving as bystanders for patients undergoing treatment (Silva, 2010; The Island, 2013). However, most of them have to stay with the patient around the clock because the patients are bedridden and need assistance all the time. Therefore, the bystanders were recruited from the hospital setting by the researcher using the snowball sampling technique. Telephone interviews were then scheduled with these bystanders.

Informed Consent

As Sri Lankan people are not familiar with research culture, they are typically reluctant to participate in research activities. Therefore, the researcher fully explained the research activities to the bystanders individually who had contacted the researcher as a result of snowballing sampling technique; the researcher invited their participation in the research via the telephone. The researcher explained the research project to bystanders who were interested in participating in the study. After they agreed to participate, informed consent was obtained. A “Consent and Authorization to Participate in a
Research Study” form was prepared in both English (Appendix A) and Sinhalese (Appendix B). According to Bailey (2007), “informed consent is necessary when the research is more than observations in public places” (p.30). Informed consent from the participants for the telephone interviews was obtained by the verbal reading by the researcher of prepared consent forms. The participant gave verbal consent to the researcher that he or she was informed about the study and agreed to participate in the study. Participants were thoroughly informed regarding their ability to withdraw or refuse to participate in this study at any time, without penalty or coercion of any kind (Roberts & Taylor, 2002). Recruitment of participants was continued until saturation of data occurred.

**Data Collection**

Data collection methods in qualitative descriptive research must be consistent with the research question and the purpose of the study and contribute to the rigor of the research (Bradshaw et al., 2017; DeJonckheere & Vaughn, 2019). Sandelowski (2000) pointed out that data collection in qualitative descriptive research is characteristically focused toward determining the who, what, and where of events or experiences, or the basic nature of the experiences. Data collection techniques in this study included individual semi-structured interviews (Sandelowski, 2000) via telephone due to the COVID 19 pandemic.
Semi-structured Interviews

Telephone interviews were conducted with bystanders to explore their perspectives on the provision of informal, hospital-based care to bedridden patients with cancer in Sri Lanka. An interview can be described as a verbal interchange, in which an interviewer attempts to elicit information, beliefs, or opinion from another person’s point of view (Burns, 2000). Adaptability is one of the major advantages of the interview, since the interviewer can follow up on ideas, probe responses, and investigate motives and feelings, leading to in-depth knowledge of the area under study (Bell, 2005).

Telephone interviews for this study were semi-structured and lasted around one hour. The main aim of the interviews was to obtain the participants’ ideas, beliefs, values, and activities regarding their role as bystanders through their own words (Rice & Ezzy, 1999). The semi-structured interviews were directed with a pre-formulated set of interview questions/interview guide which was prepared in both English (Appendix C) and Sinhalese (Appendix D). It was developed using the existing literature and the expert opinions of the committee members to contribute to objectivity and trustworthiness (Kallio, Pietilä, Johnson, & Kangasniemi, 2016). During the interview, additional follow-up probes were used for clarification and to obtain more in-depth data (DeJonckheere & Vaughn, 2019). The conceptual model of the study, which is the social-ecological model, further informed the questions for the interview guide. The three research questions addressed and matched multiple layers of the conceptual model. Research question one prompted people to talk about the interpersonal level. Research question two related to the interpersonal level, institutional level, and community level. Research question three
related to the policy level. Further, the social-ecological model was used to determine which levels the bystanders saw as important because the research cannot be meaningful if it refers to only one theory or to concepts residing within only one theory. Hence, the researcher synthesized the existing views of bystanders, from both theoretical concepts and from empirical findings. In this type of study, the synthesis may be called a model or conceptual framework, which essentially represents an integrated way of looking at the problem (Liehr & Smith, 1999). Thus, a conceptual framework/social-ecological model brings together a number of related concepts to explain or predict a given event or to give a broader understanding of the phenomenon of interest (Imenda, 2014), which, in this study, was the perspectives of bystanders.

Telephone interviews were conducted in the Sinhala language (Sinhalese), which is the native language in Sri Lanka. Rice and Ezzy (1999) highlight the value of conducting in-depth interviews in the participant’s own language because they can express their own feelings in detail and in-depth without hesitation. Further, the researcher conducted all the interviews, establishing a good understanding and rapport with the study participants. Interview skills, such as keeping silent, listening actively, and not interrupting the participants while they are talking (Rice & Ezzy, 1999) were used. All of the interviews were conducted on a date and time of the participant’s choice. The place for the interview was selected from each ward or, occasionally the bystander chose to be interviewed where they were placed next to the patient, as many were reluctant to leave their patients. The places in the ward were quiet, private, comfortable settings with minimum distractions, making it possible to get a clear recording (Edwards & Holland,
All interviews were audio-recorded using a password-protected digital recorder. The nature of participant involvement and the potential risks were explained over the phone prior to each interview as part of obtaining informed consent. This interview process was informed by preliminary data analysis steps, including thinking, planning, discussing with dissertation chair, reading notes and transcripts, sorting through data for themes, and thinking again prior to the next interview (O'Reilly, 2005).

All interviews were transcribed verbatim for later analysis. According to O’Reilly (2005), the researcher should do some of the transcribing as the process enables the researcher to identify themes and make connections. Hence, all interviews were translated into English by the researcher with the help of two nursing graduates who are currently working temporarily as nursing demonstrators in the Open University in Sri Lanka. These nursing graduates have completed their undergraduate nursing education in the English medium which includes a research course and a final year undergraduate research project. They also have extensive experience in transcribing and translating interviews as research assistants in the Department of Nursing. Hence, they have enough knowledge and skills to transcribe and translate the interviews in this study. IRB approval was obtained for these study team members.

Because the researcher’s reflective notes are typically a major component of data collection in qualitative research, this researcher wrote notes after each of the interviews with reflections on the process and outcomes. O'Reilly (2005) pointed out that the reflective notes are not only what is observed and what participants express, but also the
researcher’s thinking and feeling about what is heard and seen and the implications for the overall research study. Keeping memos of such analytical ideas helped this researcher form the beginning of the analysis process.

During this study, notes were revisited, and reflections were drawn from them, especially during the data analysis phase. Notes were further used to generate discussions with the dissertation chair. The use of reflective notes also facilitated the process of monitoring the match between the research topic, the bystanders, and their context (Hammersley & Atkinson, 1995).

**Data Management**

NVivo software for qualitative data analysis was used for this research study. According to Wolf (2007), data management is simplified by computers, scanners, digital cameras, and audio and video recordings. Using computer-based software allows data storage, coding, and efficient data retrieval. Rice and Ezzy (1999) believe this software also supports “modernist assumptions about texts being representative of people and tends to disembody interviews even further than physical transcripts” (1999, p. 204). Overall, data management with NVivo software is an easily managed process, allowing all data to be investigated together.

NVivo helped the researcher manage the data by organizing and keeping track of records, including all data files, not only from interviews but also reflections as memos; information about data sources; and conceptual maps of what was occurring in the data. By using the software, the researcher managed the ideas, queried data, created models,
and generated reports from the data as was necessary. A focus on language, communication, and interrelationship to develop meanings of the interactions was achieved within the NVivo data management process (Bazeley & Jackson, 2013). Unlike statistical software packages, the main purpose of NVivo is not necessary to analyze data, but rather to help the analysis process, of which the researcher must always remain in control. However, the researcher must know that no software can analyze qualitative data (Zamawe, 2015). NVivo is basically a data management package -- there to help the researcher during the data analysis process.

**Data Analysis**

Unlike other qualitative research approaches, data analysis of qualitative descriptive research does not use a pre-existing set of rules that have been developed from the philosophical or epistemological perspective of the discipline that created the specific qualitative research approach (Lambert & Lambert, 2012). Therefore, qualitative descriptive research is purely data-derived, in that codes are generated from the data during the study. Similar to other qualitative research approaches, qualitative descriptive studies generally are characterized by simultaneous data collection and analysis (Lambert & Lambert, 2012). Both content analysis and thematic analysis are typically used in a qualitative descriptive design study (Vaismoradi, Jones, Turunen, & Snelgrove, 2016). Nursing researchers frequently use qualitative content analysis and thematic analysis as approaches in qualitative descriptive nursing studies (Vaismoradi et al., 2013). This
Qualitative descriptive study used both approaches to analyze the data according to the research questions of the study.

Qualitative content analysis was the main analysis method used in this study. According to Sandelowski (2000), qualitative content analysis is the analysis method of choice in qualitative descriptive studies. Qualitative content analysis is reflexive and interactive; the researcher continuously modified the management of data to accommodate new data and new insights related to the bystanders’ perspectives about their roles of looking after bedridden hospitalized cancer patients. Therefore, as a common starting point of qualitative content analysis, this study’s interviews of bystanders were transcribed. According to the objective in qualitative content analysis, a large amount of text obtained from the bystanders was transformed into a brief, highly organized summary of key results (Erlingsson & Brysiewicz, 2017). Raw data from interviews transcribed verbatim were analyzed to generate themes or categories. This lead to a process of further abstraction of data at each stage of the analysis process, from the manifest and literal content to latent meanings of the types of care bystanders provided and the types of communication/interaction they had with nurses.

Parallel with content analysis, the researcher performed a thematic analysis to explore bystanders’ perspectives on provision of care and interaction/quality of communication with nurses. Thematic analysis is a method that is commonly used in qualitative designs to identify and analyze emerging themes or patterns within data (Braun & Clarke, 2006). It is further described as a descriptive method that reduces the data in a flexible way that merges with other data analysis methods (Vaismoradi et al.,
2013). Therefore, it is ideally matched for this study’s data analysis method to identify bystanders’ care provisions and the quality of their communications with nurses.

Following Braun and Clarke (2006), the researcher familiarized himself with the data from the bystander interview transcripts and commenced generating initial codes. The researcher then collated initial codes into potential themes and gathered all data under the relevant potential theme. Braun and Clarke (2006) further pointed out that the ongoing analysis will be helpful to review and refine the specifics of each theme, and the overall story revealed by the analysis, generating clear definitions and names for each theme. When presenting findings, the write-up that includes data extracted evidence provides a concise, coherent, logical, non-repetitive, and interesting account to the bystander perspective within and across themes.

According to Castleberry and Nolen (2018), in order to allow readers to trust the study’s research findings, the researcher must be transparent about the analysis process, in this case providing satisfactory details about the study’s bystander content so the reader can determine whether the findings are transferable to similar settings, to indicate consistency throughout the research to demonstrate dependability, and to ensure that the study findings emerge from the data and not the researcher’s biases. This helps to maintain confirmability. This researcher examined the trustworthiness of every phase of the analysis process, as trustworthiness is achieved across four areas: credibility, transferability, confirmability, and dependability, including the preparation, organization, and reporting of findings in order to reassure readers of the overall trustworthiness of the study (Elo et al., 2014).
In conclusion, despite various similarities between both content and thematic analysis in qualitative descriptive research, such as cutting across data and searching for patterns or themes, the key difference lies in the opportunity for quantification of data in the content analysis by measuring the frequency of different categories and themes, which may stand as a substitution for significance (Vaismoradi et al., 2013). Therefore, in this research study, content analysis was used to explore the types of care bystanders provide and the types of communication/interaction they had with nurses, while thematic analysis was used appropriately to explore bystanders’ perspectives on care provision and interaction/quality of communication with nurses.

**Ethical Considerations**

All research studies have potential risks to participants. It is the responsibility of the researcher to ensure that participants are protected against such risks. Hence, approval by the Human Research Review Committee (HRRC) at the University of New Mexico Health Sciences Center (HSC) was obtained (Appendix E) for this study to conduct telephone interviews, using the snowball sampling method, with the bystanders who were with bedridden patients with cancer. Snowballing sampling and telephone interviews were new changes due to coronavirus pandemic situation. The recruitment letters and consent forms were translated by an accredited English/Sinhala translator and also approved by the UNM HRRC.

Permission to conduct the research at the Cancer Hospital in Sri Lanka was required. The hospital does not have an ethics committee, so the researcher initially
obtained a letter from the Director of the Cancer Hospital for permission to conduct the research (Appendix F). This approval had been deemed appropriate by the UNM Human Research Protections Office (HRPO) pre-study consultant. This study also included key personnel, such as section matrons, ward managers, ward consultants, and ward nurses who explained the study and the role of the researcher where and when that was necessary.

Confidentiality and privacy of all participants' information was maintained in this study during the period of data collection and also in the writing of reports. Originally, interviews were going to be face-to-face, but due to coronavirus, they were conducted over the telephone. Hence, it was advised to the bystanders to select a convenient date and time within a calm and quiet place to protect their privacy. Collected data is reported in this study with no identifying information; not even the name of the ward has been used. Confidentiality was also maintained with consent forms securely stored with the researcher, separate from the primary data. Pseudonyms were used for the participants to maintain confidentiality. All collected data was stored under a password-protected folder in the researcher's personal computer. Any form of hard copies/transcripts were kept in a locked cabinet in the office of the Department of Nursing, the Open University of Sri Lanka, during the period of data collection. After completion of the data collection and analysis, primary data was transferred to the University of New Mexico School of Nursing research data storage area according to the stipulated guidelines.
**Novel Coronavirus Disease**

The World Health Organization (2020b) (WHO) announced that pneumonia of unknown cause was identified in the city of Wuhan in Hubei province, China, on 31st December 2019. According to the authorities, some patients were trading dealers or suppliers in the Huanan Seafood market. It was identified as a novel coronavirus that caused pneumonia. These patients were soon identified to be infected by a novel coronavirus that was initially named the ‘2019 - novel coronavirus’ (2019-nCoV) on 12th January 2020 by WHO and later named ‘Severe Acute Respiratory Syndrome - Coronavirus – 2.2’ (SARS-CoV-2.2) (Ren et al., 2020).

**The Epidemic of Coronavirus Disease**

According to the WHO (2020b) officials, a case of the novel coronavirus was confirmed in Thailand on 13th January 2020. The WHO was not surprised that incidents of the novel coronavirus would arise outside of China. However, as of 31st January 2020, this epidemic had spread to more than 19 countries, including Sri Lanka with 11,791 confirmed cases and 213 deaths (Adhikari et al., 2020; World Health Organization, 2020a). Accordingly, the 2019-nCoV outbreak was declared as a Public Health Emergency of International Concern by the WHO Director-General, Dr. Tedros Adhanom Ghebreyesus, on 30th January 2020.

Meanwhile, the WHO (2020b) proposed and mandated guidelines that the name of this new disease could not refer to a geographical location, an animal, an individual, or a group of people. This option would help guard against the use of other names that could
be erroneous or stigmatizing. Accordingly, the WHO declared the disease’s official name as “Coronavirus disease 2019,” abbreviated to COVID-19, on 11th February 2020.

According to the WHO (2020b) assessment, by the end of the third week of February 2020, approximately 40 countries in Africa and 29 in the Americas had detected COVID-19. Hence, based on the lessons learned from the influenza type A virus (H1N1), a respiratory infection that was popularly named swine flu, and Ebola, formerly known as Ebola hemorrhagic fever, the WHO outlined considerations for organizers of mass gatherings. It has also released advice on how to identify and take care of ill passengers who are suspected of having COVID-19.

Based on the assessment of this outbreak and concern due to both the alarming levels of spread and severity, the WHO assessed that COVID-19 could be characterized as a pandemic. This was the first coronavirus pandemic declared by the WHO, which happened on 11th March 2020. COVID-19 has spread to more than 200 countries, from China to European countries, such as Italy, Spain, and France. It has further strongly influenced the United Kingdom and the United States of America. In mid-June 2020, there were more than eight million confirmed cases and confirmed deaths were around 450,000 among 216 countries around the world (World Health Organization, 2020b).

**Sri Lankan Situation with Coronavirus Disease**

When considering the Sri Lankan situation, the first confirmed case of coronavirus was reported on 27th January 2020. The patient was a Chinese national who came to Sri Lanka as a tourist (Epidemiology Unit-Ministry of Health, 2020b). Six weeks
after the first patient was identified, a second case was confirmed on 11\textsuperscript{th} March 2020 (Epidemiology Unit-Ministry of Health, 2020c). Since then, the outbreak has gradually accelerated, reaching more than 2,000 cases and 11 deaths by mid-June 2020 (Epidemiology Unit-Ministry of Health, 2020a).

However, the government of Sri Lanka instigated a number of quick actions that kept the situation under control. Early on, the government provided facilities to house students who had been studying in China. To reduce and prevent social contact and individual movement, the Sri Lankan airport has been closed and continuous curfew imposed. High-risk areas have been identified and locked down. People who were suspected of being high-risk were separated and quarantined in a specially identified place. Sri Lankan armed forces are managing those quarantine centers. Further, the Ministry of Health has taken a variety of measures to provide medical facilities that include testing and high-risk patient isolation. Persons who have come into contact with infected patients have been advised to self-quarantine in their houses. In addition, community programs are providing health services to patients who are unable to access health facilities. The government has introduced a number of stimulus packages to prevent a financial crisis. However, even amidst all these measures, there is still a risk of further spread of the virus (Epidemiology Unit-Ministry of Health, 2020a).
Influences of Coronavirus Disease on This Study: Study Setting, Recruitment and Data Collection

With the pandemic situation in Sri Lanka, most hospitals were limited to emergency care and were ready to accept COVID 19-suspected patients, including the Apeksha/Cancer hospital, which was originally planned as the study setting of this study. Hence, they had limited visitors entering the hospital. The researcher also had to face this situation. Therefore, it was not possible to conduct face-to-face interviews with the bystanders who were in the cancer hospital. As a result, the data collection method had to change from face-to-face interviews to telephone interviews. Further, the purposive sampling method changed to the snowball sampling method to facilitate sample recruitment. Accordingly, additional IRB approval was received to conduct telephone interviews with the bystanders who were with bedridden patients with cancer through the snowball sampling method.

The recruitment resulted in a study sample of 17 participants. All the interviews were audio-recorded, transcribed verbatim, and translated to the English language for data analysis. According to O'Reilly (2005), the researcher needs to engage with some of the transcribing as the process facilitates identifying themes and making connections. This researcher was involved with the transcribing. As a result of the thematic and content analysis, findings are presented following the main themes and the information that was relevant to each of the three research questions, guided by eight interview questions.
The Rigor of the Study

Any systematic effort at description and explanation, whether quantitative or qualitative, must address several critical questions for better evaluation (Silverman, 2006). In a research study, regardless of design and method, the researcher must clearly state the evaluation criteria for the study’s methodology (Silverman, 2006). In addition, nurse researchers need to consider the true value of the research and demonstrate that it is credible and valid for nursing practice (Holloway & Wheeler, 2002).

Even now, there is considerable debate over the criteria for maintaining rigor in qualitative research (Cypress, 2017; Leung, 2015; J. M. Morse, Barrett, Mayan, Olson, & Spiers, 2002). According to J. M. Morse et al. (2002), without rigor, research is valueless and becomes fiction and loses its utility. Hence, reliability and validity are two key aspects of all research. Reliability is the idea of replicability (Golafshani, 2003; Johnson & Pennypacker, 1980; Winter, 2000), repeatability (Golafshani, 2003; J. Morse, 2012), and stability of results or observation (M. M. Leininger, 1985). The issue is that human behaviours and their meanings in qualitative research are never static or the same, just as measurements and observations can also be repeatedly wrong (Cypress, 2017) due to the changing nature of humanity, time, and circumstance.

Validity in research is concerned with the accuracy and truthfulness of scientific findings (Van Manen, 2016). Campbell and Stanley (2015) have defined two major forms of validity: internal and external. Lincoln and Guba (1985) used the distinction between internal and external validity and applied it to qualitative research. Internal validity is used to refer to the extent to which research findings are a true reflection or
representation of reality rather than the effects of extraneous variables. External validity addresses the degree or extent to which such representations or descriptions of reality are legitimately applicable across groups.

However, many qualitative researchers avoid validity and reliability and use terms such as credibility, trustworthiness, applicability, truth, value, consistency, and confirmability when considering criteria for evaluating the scientific merit of qualitative research (Glaser & Strauss, 1967; M. Leininger, 1992; Lincoln & Guba, 1985). It must be understood that any attempt to synthesize or appraise different studies under one system is impossible and conceptually incorrect (Leung, 2015; Noble & Smith, 2015). In Lincoln and Guba’s vital work in the 1980s, reliability and validity were considered conceptually grounded in the quantitative framework and not transferable to a qualitative framework. Lincoln and Guba (1985) were the first to replace validity and reliability with the concept of trustworthiness to evaluate the rigor of qualitative research. Trustworthiness is achieved across four areas: credibility, transferability, confirmability, and dependability.

Credibility or confidence is described as the quality of the data achieved through sample selection and presenting faithful descriptions and interpretations of participants’ experiences (Lincoln & Guba, 1985; Lincoln & Guba, 1989). Lincoln and Guba described additional techniques, such as prolonged engagement, persistent observation, triangulation, peer debriefing, negative case analysis, referential adequacy, and member-checking, that can be used to establish credibility. In this study, the researcher achieved credibility by building good relationships with the bystanders, which enabled and established the trust through which misinformation or distortions were clarified. Member-
checks of data occurred, and further discussions with dissertation committee members confirmed the credibility of the data. Additionally, the theme list developed from the literature provided confidence in the data collection process and is reflective of the purpose of the study.

Transferability refers to the extent to which the findings can be transferred or applied to other similar settings or groups (Lincoln & Guba, 1989). While qualitative research does not aim to be generalizable (Holloway & Wheeler, 2002), the findings need to be evaluated in relation to their applicability to other similar settings or populations. Thick description supports the transferability of the data. Thick description (which is not limited to ethnographic design) is described by Lincoln and Guba (1985) as a way of achieving a type of external validity. Hence, the researcher evaluated the extent to which the conclusions drawn were transferable to other times, settings, situations, and people by describing a phenomenon with contextual detail. In this study, transferability was achieved by evaluating findings in relation to their applicability to other parallel cancer care settings in which bystanders are available, as well as other cancer treatment units in other similar hospital settings in Sri Lanka.

Dependability refers to the stability of data over time and conditions (Lincoln & Guba, 1989). To be more specific than the term reliability, Lincoln and Guba used dependability in qualitative research, which closely agrees to the notion of reliability in quantitative research. They further emphasize inquiry audit (p. 317) as one measure that may enhance the dependability of qualitative research. Further dependability can be achieved by having expert qualitative nursing researchers to review the transcribed
material to validate the themes and descriptors identified from the study (Cypress, 2017). In this study, dependability was achieved by validating the findings related to the themes. A colleague was asked to review some of the transcribed materials. Any new themes and descriptors introduced by my colleague was acknowledged and considered. It was then compared with my own thematic and content analysis from the entirety of the participants’ transcribed data. If the theme recognized by the colleague did not appear in my own analysis, both analysts decided not to use it. Both analysts agreed on the findings related to themes and meanings within the transcribed materials.

Confirmability means that the research is free of biases and relatively value-neutral (Holloway & Wheeler, 2002; Lincoln & Guba, 1985). Confirmability can be met by maintaining confirmability audit, audit trails, triangulation, and reflexivity. Maintaining a reflexive journal during the research process to document introspections daily would also be beneficial and pertinent during the study (Cypress, 2017). In this study, confirmability was achieved by an audit trail that examined the processes through which data was collected and analysed, and interpretations were made. The audit trail was in the form of documentation (the actual interview notes) and a running account of the process (the researcher’s daily reflective notes). The researcher-maintained self-awareness of his role as the sole instrument of this study. After each interview, he worked in a calm and quiet place to document additional perceptions/reflections and recollections from the interviews.

Through developing these practices, the researcher ensured the trustworthiness of the study. Trustworthiness in qualitative research denotes methodological soundness and
adequacy (Holloway & Wheeler, 2002; Lincoln & Guba, 1985). By rigorously following the research process and being supervised by nursing research and other expert faculty, methodical trustworthiness was further achieved.

**Limitation of the Study**

The results of this study cannot be generalized to all hospitals in Sri Lanka since data was only gathered from the cancer hospital. However, the results provided insights into the current role of bystanders at the cancer hospital and can be transferred to similar settings.

A further limitation is that this study was focused only on bystanders’ perspectives and descriptions; there was no theory development or identification of relationships. It did not include collected data from the patients or health care workers, including nurses.

The change in sampling, purposive to snowballing sample that the researcher made due to the pandemic situation, may have affected to the study sample composition a bit. As an example, the sample of the study was ended up with mostly family/friend bystanders than the paid bystanders.

Due to the lack of a research culture in Sri Lanka, some participants were reluctant to explore important matters related to their practice. The interviews were new experiences for some. For some informants, this was their first experience participating in a research study.
Conclusion

The study methodology related to the study of bystanders’ perspectives on the provision of informal, hospital-based care to bedridden cancer patients in Sri Lanka has been described in this chapter. In this qualitative study, a qualitative descriptive study design was used. Data collection was performed in the community setting close to the cancer hospital in Maharagama, Sri Lanka. The study sample was purposefully selected bystanders who provide care for hospitalized, bedridden cancer patients. After obtaining ethical approval and informed consent, semi-structured, in-depth interviews were conducted with selected bystanders in a pre-negotiated time and the place that was comfortable to the participant. All interviews were audio-recorded and translated to the English language for study purposes. Data was analyzed using both content and thematic analysis methods according to the nature of the research questions. The researcher’s personal, professional, and academic experiences in the field of cancer care was reflected upon and utilized to successfully conduct the study. Chapter Four presents the research findings, and Chapter Five presents the research, clinical, and policy implications of the study.

Definition of Terms

1. Bystander

A bystander is a person who is standing near and watching something that is happening but is not involved in it (Cambridge Dictionary, 2019). According to Pallium India (2019), the bystander is a relative who endlessly stands by anyone who is admitted
to the hospital. In this study, a bystander is an informal caregiver who helps to fulfill day-
to-day activities, particularly palliative care for cancer patients who are bedridden and
admitted to the cancer hospital. These bystanders are family members, close relatives,
friends, or hired persons.

2. Bedridden Patient

Confined to bed because of illness or infirmity. In this study, bedridden patients are in the last stages of cancer and may require end-of-life care.

3. Cancer Patient

Cancer is a generic term for a large group of diseases characterized by the growth of abnormal cells beyond their usual boundaries that can then invade adjoining parts of the body and/or spread to other organs (WHO 2019). Study participants are patients with cancer. This study will not collect the patients’ diagnoses; they are admitted to a cancer hospital for treatments.

4. Informal Care

Care that is provided to the very young, the very old, the weak, the poor, and the sick by family, friends, neighbors, and concerned citizens, rather than by trained, licensed, or certified health care professionals (Medical Dictionary, 2009). In this study, informal care is provided by bystanders.
5. Interaction

The act or process of interacting. A mutual or reciprocal action or influence (American Heritage Dictionary of the English Language, 2011). In this study, the bystanders' interactions with the patients, nurses, and family members will be explored.

6. Perspective

A perspective is a particular way of thinking about something, especially one that is influenced by someone's beliefs or experiences (Collins English Dictionary, 2019a). In this study, bystanders’ perspectives will be explored.

7. Policy

A policy is a set of ideas or plans that are used as a basis for making decisions, especially in politics, economics, or business (Collins English Dictionary, 2019b). In this study, policies will be explored or suggested according to the study findings related to the practice of the role of bystanders and its importance to the health care system in Sri Lanka.
CHAPTER 4
FINDINGS

This chapter presents the findings of the study that evolved from the data analysis, which followed content and thematic analysis methods. A detailed description of analysis methods has been provided in chapter 3. This chapter presents the themes identified through the data analysis as study findings in a format that demonstrates the richness of the data.

Study Participant Characteristics

A total of 17 bystander participants were interviewed by the researcher for this study. Even though the initial plan was to recruit 20 participants, participant recruitment was discontinued after 17 bystanders had been interviewed due to the saturation of data. The bystanders mainly belonged to two categories: paid and unpaid. There were 12 unpaid and five paid bystanders. Among them, 13 were female and four were male. All the bystanders were in the range from 21 to 63 years of age. However, nearly half of them were older than 50 years. Of the unpaid bystanders, all were close family members with only one being a close friend of the patient. There was a unique bystander who was from the Sri Lanka Army. Further, 14 bystanders came to Colombo from distant cities and villages in Sri Lanka. All the bystanders had no prior training for informal caregiving. Contrary to the researcher’s expectations, there were no retired health care workers, such as attendants, or professionally trained bystanders, within the sample.
Research Question One – Bystanders’ Perspectives

The first research question for this study was “What are bystanders' perspectives on providing informal care for bedridden patients with cancer in hospital settings in Sri Lanka?” This question was answered by asking the following four qualitative interview questions.

Question 1A: Please Tell Me How You Became a Bystander

Participants reported that they became a bystander under various circumstances. The responses differed based on whether the bystander was unpaid or paid. Accordingly, the findings uncovered how they became a bystander in the cancer hospital to look after bedridden patients with cancer.

Unpaid Bystanders

Unpaid bystanders do not work for money. The study findings revealed that they were voluntarily acting as bystanders and were mostly relations or friends of the patients. Some organizations, such as the Sri Lanka Army, assigned persons to work as bystanders.

The Responsibility of Family Bonds and Friendship Caused Some to Become Bystanders.

Most of the time, the researcher noticed that the patient’s closest relation served as a bystander. Mothers, fathers, daughters, sons, daughters-in-law, and close friends were identified among the bystander participants who were interviewed. They all
highlighted the family bond and friendship as key motivating factors for becoming bystanders.

One mother highlighted how she had to become a bystander for her son due to their heartfelt relationship. Her son was separated from his wife and no one was looking after him, so she had taken that responsibility, which presented many difficulties:

Certainly, I am looking after my son. He was diagnosed having oral cancer six years ago. Initially, it presented in the upper palate. Now it has spread all over the face. Surgeries were done for it several times. A tube was inserted after doing the last surgery. The surgery site is also soiled and having a bit of a bad smell. Now he can’t eat, he can’t even take a sip of water from the mouth. He seems very weak. If he is seated in a chair, he says he is not fit, and he shivers.... Further, his wife separated around 10 years ago. Hence no one to look after him. He is my son. So, I have to look after him. No choice for me.

The unpaid bystander role is performed not only by mothers; fathers have to become involved when certain circumstances occur. One father described how he had to become a bystander to look after his eldest son:

Actually, I am not a professional bystander. But I have to become a bystander to look after my son. I am looking after my eldest son who had undergone surgery for removing a tumor inside the brain. ... I didn’t go home for two months as my son couldn’t speak properly since the right side of his body was paralyzed. Since the first day my son got admitted to the hospital for undergoing the surgery, I was
with him. This time my friends in the village cropped harvest of my paddy fields on my behalf.

The father described how mutual support of village friends enabled him to leave his livelihood to care for his son. Accordingly, parents look after their children when they become bedridden and need palliative care, especially in the hospital. Vice versa, when parents become patients and need palliative care, children often look after them. This family bond was clearly highlighted by one of the daughters who looked after her mother in the cancer hospital:

I am looking after my mother. She is 67 years old. Currently, she is suffering from cancer inside the pancreas. As doctors mentioned, there are nodules placed corner of the pancreas and another 8 nodules are located outside the pancreas. First diagnosed this 5-6 months ago. .... I have experience in caring for the mother for about 5 months. Before that also mother was hospitalized. Everything such as feeding was done by me. .... Before I look after my mother I haven’t such experiences. As I have two brothers and I am the only daughter, I take over to look after my mother. That’s how I became an informal caregiver to my mother.

This bystander emphasized that her status as a daughter informed her responsibility to be the caregiver instead of her male siblings.

Another participant was a son who looked after his father. Even though this son is a father of two children, he gave all the responsibilities to his wife and later to his mother because he wanted to look after his father as a bystander:
Actually, I am not a permanent bystander. I am looking after my father who is on light therapy (radiotherapy) for the spinal cord area as a result of paralyzing both legs... Then we have taken him to the hospital on the eighth morning. Father has transferred to the general hospital in the evening on the same day. Then after the investigations, father had to face surgery on Sunday. ... After confirmed that the father is having cancer on Tuesday, again transferred to the cancer hospital.... What to do? I am his only son. I have to look after him. I came from another area. I am married and have two children. I have a meat shop. I am working there. My wife is an Ayurvedic doctor. When I came to stay with my father, I handed over all responsibilities of my children to my wife. But unfortunately, due to the current situation of COVID-19 in our country, she was asked to go to work. So now my children are at my mothers’ home.

Thus, many family members can be affected by one bystander’s service. Further, the findings of the study revealed that not only the closest family members, such as mother, father, daughters, and sons but also daughters-in-law are involved in informal caregiving as bystanders. It seems that if there is no daughter in a family, the daughter-in-law takes the responsibility to look after the husband’s parents. One unpaid bystander explained:

> I am looking after my mother-in-law. Earlier she had cancer in the ovaries. It has removed. Then now she has a tumor in the intestine. After undergoing the surgery, we carried her home. Then we visited the clinic, and they asked to admit again. So, this time she got admitted. Since then, I and my sister-in-law have been
looking after the mother time to time like using shift method. Since I am on medication for high blood pressure, it is really difficult to stay continuously. Luckily, our mother has three sons. I married the eldest son.

Study findings not only emphasized the family bond, but also the bond of friendship. For example, one woman became a bystander to look after her friend’s mother because his wife was reluctant to provide care, and the friend’s mother refused the care of her daughter-in-law:

I am looking after my best friend’s mother. She is 69 years old. Currently, she is suffering from cancer in the intestine. My friend is her son. He is the only child she has, and his wife is not willing to look after mother-in-law. This mother also refuses to stay with her daughter-in-law. I and my husband have known them for 10 years. My son is also studying with our friend's son in the same class. Further, we are doing business together. This lady has suffered from intestinal cancer since March 2019. No operations were done as she is now 69 years old. Earlier she got six injections and at that time she was not weak. But this time she had three injections so far and now she can’t walk. She is completely bedridden from yesterday. So, I came and looking after her as my mother.

This dedication on behalf of the friendship was further elaborated by another participant:

I am a Sinhala Catholic. But this lady is a Buddhist. His son and I are doing business. I have a son. My mother died due to an accident 23 years ago. So, I didn’t have a chance to look after her. Therefore, I like to take care of old ladies. My husband is doing all kinds of household things in my absence while looking
after my son. He always gives courage to me to conduct this activity free of mind. My husband is also used to come to the hospital to see her frequently when he could. But these days due to the COVID-19 curfew, he can’t come.

She did not discriminate due to the different religious backgrounds or her family commitment. Her husband was also helpful. She lost her mother a long time ago, so she felt that caring for this mother was like caring for her mother.

Overall, the study findings highlighted that the relatives and friends became bystanders mainly due to the strong bond of family and friendship. Their responsibility to look after their loved ones is informed by gender roles and generational roles in families. Close friends became bystanders in the absence of available relatives to care for their friends.

**Military Personnel Instructed to Care for a Colleague**

The findings also identified that military forces have a mechanism to provide bystanders when their staff members are hospitalized, bedridden, and need palliative care:

*I am working in the Sri Lanka Army. I look after a friend working with me at my camp. He has cancer in the spinal cord. Now he couldn’t move his body and he is bedridden. Actually, I came to know him after joining the army. He is my job mate. So, I have to come and look after him when he admits to the hospital. .... I have been assigned to do so. Patients from the army can request a bystander from the army, and normally they assign one person like me to work as a bystander.*
The soldier in this study acted as a bystander like a relative or friend. He was also untrained in formal caring but was assigned to look after an army colleague. He further pointed out that, when a member of the army is severely sick and hospitalized, he or she can request a service person to act as a bystander at the patient’s bedside.

This is a unique situation that was identified in the study. It is a helpful mechanism that was adopted by the army. This is further evidence that if a person becomes bedridden and hospitalized due to some disease condition, he or she needs a bystander or informal caregiver rather than expecting the hospital staff to provide full care.

Paid Bystanders

Paid bystanders in this study work for money. It is employment. Some paid bystanders work as independent workers, whereas others have joined an agency and are known as agency bystanders.

Dissatisfaction with Previous Work

Some paid bystanders initially worked in different factory positions. When they became dissatisfied with the factory work conditions, they tried to find another job opportunity. At one point, they got work from the bystander agency, but some now have become independent. One paid bystander initially worked in a tea factory:

*Actually, I came to work in the tea factory... With time we came to know that the factory is not paying us well though we worked very hard. Then we looked for*
another job opportunity. .... Finally, we searched in the newspaper and saw a post on 'Bystander Service'. Then we called and went to that place. .... One day the agency asked me, did I like to work in the cancer hospital since there was a vacancy. So, I ended up here like that. I think this is my twelfth year in this cancer hospital. Now I am not belonging to any agency and do the independent service.

Further, another bystander described working at several workplaces before she ended up as a bystander. After she left three workplaces, she joined an agency to serve as a bystander:

*Previously I worked as a machine operator in a garment factory. After the garment factory, I went to work in another company, Meanwhile, I saw this caregiving company advertisement in the newspaper. Then I talked with the manager and joined this bystander company/agency...with a friend. Then before I came to this hospital, I did home nursing, too, as I like this field.*

These findings showed dissatisfaction with previous workplaces. This dissatisfaction encouraged people to find suitable employment and they chose to become bystanders. Only one participant described prior paid informal caring work.

**Became Interested in Making More Money**

Further, all paid bystanders left their previous workplaces hoping to make more income as bystanders. Usually, they would get information from one of their friends who understood the informal caregiver field. One paid bystander explained how she switched from her previous practice to this paid bystander service:
My husband passed away. I have a son, but he doesn’t care about me. So, I have to find some income by myself. Therefore, I moved here, and first I worked in a house. My responsibility was to look after an old lady. At that time, I have met another maid in that house. She told me regarding this job and she also told me...I can earn more money than what I can earn working in a house. Therefore, according to her guidance, I could be able to find a company/agency which hired bystanders. Initially, I joined that company. Now I am working for another company/agency.

Another bystander also explained how she gave up agency work and became an independent bystander to make more money.

...my first thought was not to attend as a bystander since the cancer was believed to be deadly at that time. But at last, I became the person who would never leave the hospital. When I was working in the same ward over and over again, the nurses said that “why are you working so hard and yet paying the agencies. You can work alone and earn. You can come as a private /independent bystander. You can stay in the ward.” With that invitation, I left the agency and started work as an independent bystander.

These findings highlighted that these bystanders wanted to make more money by providing paid bystander services. According to these paid bystanders, this is employment that can provide a higher income than their previous jobs. Further, some paid bystanders became independent bystanders to earn more money, rather than paying
extra money to the agencies. The recommendation of a ward nurse helped one bystander become a permanent, independent paid bystander.

**Own Initial Intention to Become a Bystander**

Many of the paid bystanders originally intended to become a caregiver or wanted to join the health care field. However, due to various reasons, they were not able to do so when they began working. As one bystander explained, “I have been expected to help people for a long time ago. I wanted to become an attendant, but my father didn’t let me.” Therefore, when some get the chance to become a paid bystander, they happily accept. Another bystander had some previous experience that influenced her to choose the caregiving service:

*Previously I didn’t know anything about caregiving. My mother got sick. At that time, I didn’t even know how to turn her. There is a way of turning a patient. But I didn’t know. Now I know any method of turning a patient. Even though the patient is bedridden it doesn’t matter. I thought that no matter what job I have done, there is no use if I couldn’t develop the skills in caregiving and how to look after a patient properly. So, I thought to stay in this field and stay continuously.*

Overall, findings highlighted that paid bystanders chose informal caregiving due to dissatisfaction with previous work, their initial interest in caregiving, and the necessity to earn more money.
Question 1B: Please Tell Me All the Various Things You Do to Help Take Care of the Patient

All the bystander participants, whether paid or unpaid, described the following routines when they provided care to patients. Some bystanders noted additional care tasks required for their particular patients. The care delivered by the bystanders around the clock was divided mainly into the morning, noon, afternoon, and evening and overnight care; the findings are presented here.

Morning Care

Morning care typically started when the patient awakened. It was usually around 5 to 6 AM. One patient and the bystander reporting awakening at around 4:00 AM. One Muslim bystander stated that he used to have daily prayers four times per day, which he performed while sitting in his chair at the patient’s bedside, even in the early morning before beginning patient care activities.

Bystanders would then bring their patients to the toilet, if they were able to transport them using a wheelchair. They helped the patient sit down on the commode and perform toileting. They then helped the patient brush their teeth and they washed the patient’s face and body. After that, they changed the patient’s clothes, if necessary. After this, they brought the patient back to the bed, helping and supporting the patient using a wheelchair. This required some lifting and transferring skills. Findings highlighted that the bystanders do all of these tasks alone.
For those patients who could not get out of bed into a wheelchair, bystanders needed to do the cleaning and essential care at the bedside. Hence, the bystanders provided the baths while the patients were in bed, using a wet towel or piece of cloth to wipe the whole body gradually with soap and water. While they performed the bath, they also removed or changed the patient’s diaper, if necessary. If the patient requested it, they gave the patient a bedpan to pass stool and urine before they were bathed. The bystander then removed and cleaned the bedpan. One bystander pointed out that he used cotton balls to clean the patient’s perineal area after passing stools. If the patient had a catheter, the bystander emptied the urine bag. One patient had a colostomy bag. The bystander would empty it in the morning. Further, if the patient had bedsores or pressure ulcers, experienced paid bystanders applied a temporary dressing after washing the wounds within or after the bath. After the bath, the bystanders applied cologne and talc powder, especially in the pressure point areas, including the patient’s backside. Some of the bystanders massaged the pressure point areas. After these detailed activities, the patients were ready for their breakfast.

All bystanders offered breakfast to the patients and helped them reach the breakfast tray. Some bystanders just brought breakfast to their patients, but others had to feed the patients because the patient could not feed himself or herself. Usually, breakfast for the patient was supplied by the hospital free of charge. However, some patients did not like it and they asked bystanders to go buy breakfast from the hospital canteen or outside the hospital. If visitors came to see the patients, they sometimes brought homemade foods. Further, some patients had nasogastric (NG) tubes that were inserted
from the nose to the stomach; other patients had percutaneous endoscopic gastrostomy (PEG) tubes, which were directly inserted into the abdomen. In that case, bystanders prepared or brought a liquid diet, such as kanji, soup, or milk, and fed to these patients. Most bystanders had no previous experience and developed the skills to feed via these tubes. They did this by themselves.

After breakfast, the bystanders gave patients their medications. Nurses distributed the morning doses of medicine around 8:00 AM. Findings highlighted that all medicines were given to the bystanders and nurses asked the bystanders to give them to the patients. The bystanders helped the patients to take their medication. Some of them put the tablet form medications into the patient’s mouth and helped them with drinking water. If the patient had an NG or PEG tube, they crushed tablet medicines and gave them with the morning feeding via the tube.

Next, the bystanders facilitated or prepared the patients to take a rest on the bed. However, instead of leaving the patient at this time to take a break, bystanders stayed with the patients because during this time doctors typically conducted their morning ward rounds. One bystander wanted to listen to the doctor’s comments and answer the doctor’s questions because the patient was unconscious. Further, the paid bystander wanted to report the doctor’s communication to the patient’s visitors. Unpaid bystanders also stayed with the patient because they wanted to understand their patient’s progress and present the patient’s problems or discomforts to the doctors. Hence, this was understood as a bystander’s responsibility.
After morning ward rounds, doctors sometimes ordered tests, such as X-rays and radiotherapy, and gave referrals to get other experts’ opinions. Nurses would then send the patients for those tests and referrals. Consequently, the bystander needed to prepare the patient, transfer the patient to a trolley or wheelchair, and then would take the patient to the tests and referrals. The bystanders usually were able to get a supportive staff member to assist and accompany them.

If both the patient and the bystander were in the ward after rounds, the bystander prepared tea for the patient or would obtain it from the hospital around 10:00 or 10:30 AM. The tea was often given to the patient with biscuits. Some bystanders prepared or bought soup or juice for patients with NG and PEG tubes. After tea, the patients rested on their beds until lunchtime. One bystander used this time to talk to the patient, read books aloud to the patient, and listened to the patient’s stories.

These were the usual morning care routines practiced by bystanders, identified in this study as findings. The noon and afternoon care were also identified, as follows.

**Noon and Afternoon Care**

Most of the time, the bystanders fed lunch to their patients. If visitors came to see the patient, they sometimes fed the patient. Some bystanders were able to go out and get some rest during visiting hours by handing over patient care tasks to the visitors. If the patient was from far away and had no visitors, bystanders would get food for lunch from the hospital or bought it from the hospital canteen. Usually, lunch was rice and curry, but it varied according to the patient’s condition and desires. Hospitals normally delivered
rice and curry for lunch. Patients with NG or PEG tubes received liquid diets such as soup, kanji, or milk. One bystander pointed out that his father used to get fruit for his lunch.

After lunch, some patients needed to use the toilet and liked to get a small wash. The bystanders would then bring them to the toilet or the washroom using a wheelchair. Bedridden patients who could not move used a bedpan and the bystanders gave them a body wash on the bed. The bystanders also changed diapers if needed and emptied colostomy and urine bags.

Around 2:00 PM, nurses distributed afternoon medications. The bystanders took the medication from the nurses and gave it to the patients. After this, most patients napped until evening tea, which was served at around 3:00 or 3:30 PM. Some bystanders prepared their own tea using boiling water that was taken from the ward pantry; they often also provided tea for the patients. Other bystanders brought their flask of tea prepared at home. Some bystanders brought tea prepared by the hospital canteen. They also provided something for the patients to eat with tea, such as biscuits.

After teatime, patients again had rest time. Some bystanders used this time to talk to and listen to the patients. Some read a book or newspaper to the patients. Noon and afternoon care described by bystanders have been presented here, followed by evening and overnight care, which is described in the following section.
**Evening and Night Care**

The hospital served dinner around 5:00 PM. This early dinner was fed to the patients by the bystanders. Patients with NG and PEG tubes were fed a liquid diet, as mentioned earlier.

After dinner and before going to bed, some patients again needed to go to the toilet and also requested a small wash and change of clothes. The bystanders would take them to the toilet or the washroom using a wheelchair. Bedridden patients were given a bedpan and a body wash on the bed. The bystanders changed diapers and clothes if that was necessary and emptied colostomy and urine bags.

Around 8:00 PM, nurses distributed the nighttime medications for the patients. The bystanders received the medications from the nurses and gave them to the patients. If patients on NG or PEG tubs had tablet medications, the bystanders crushed it and fed it to patients via the tubes, as described earlier.

Because some patients had early dinners, bystanders served them a cup of tea or milk with biscuits at night. Some patients requested that bystanders apply balms or ointments for the patients’ aches and pains before they went to sleep. The unpaid bystanders remained with their patients, sitting on a bedside chair the entire night, fulfilling the patient’s requests when necessary, such as providing water or bedpans and urinals. Many paid bystanders were ready to address those tasks upon the patient’s request, even while they were sleeping on a piece of cardboard on the floor close to the patient’s bed.
Overall, the bystanders, whether paid or not, had to cover all the routine tasks described above from morning to night or around the clock. Within these routine tasks, bystanders maintained their own personal hygiene, such as getting a wash, and they took their own meals, tea, and sometimes their medications. Overall, the findings show that almost all personal care tasks for bedridden patients were done by bystanders.

**Question 1C: When You are Helping to Care for the Patient, What are the Challenges or Difficulties You Experience?**

This question explored the challenges and difficulties faced by bystanders when they engaged in the caring process. While providing informal care for these bedridden patients with cancer around the clock, some faced challenges and difficulties, such as lack of proper training about essential caring activities, lack of support, and lack of basic facilities in and around the ward.

**Lack of Training or Orientation**

All bystanders had no proper or professional training related to informal caregiving. Paid bystanders developed some skills through their experiences and did not experience any challenges. However, many unpaid bystanders were close relations or friends of the patients and this was the first time they had acted as a bystander to look after their hospitalized loved ones. They had received no training to care for these patients and faced challenges in handling and looking after their patients.
Many bystanders, paid or unpaid, felt nervous when they were starting work as a bystander due to a lack of training. One unpaid bystander who was the father of the patient explained his situation as follows:

...At the beginning, he always urinated and defecated on the bed itself, and also, he was not able to turn. I felt nervous and I had to face some sort of difficulties there. .... When giving a bed bath to my son...I faced difficulties too...how to do it.

At the beginning of her time as a bystander, one participant used to watch other bystanders and follow their leads. Further, she practiced how to wear a diaper at home before she came to the hospital with her mother. This self-learning activity was explained as follows:

I was a little scared because I did this role the first time in my life. As I said, I have not any experience about look after a patient. So, I watched what the others were doing and followed them. We practice wearing diapers at very first at home. Not in the hospital. I and my other two sisters-in-law train how to change the diapers there. The diaper packet itself mentioned the way how to wear and change it. So, it was not a problem.

Further, the initial fear about working as a bystander occurred due to a lack of training or experience. One paid bystander participant highlighted the challenges she felt when she started her career as a bystander.

At first, when I started work as a bystander, I had some fear and I was afraid.

When I was turning the patient, I always feel whether the patient would fall....
“What should I do to take care of the patient? What should I do when the patient is not eating?” These questions were always in my mind.

These fears often worsened when the bystander had to perform special procedures. One unpaid bystander described the situation that he faced when he had to empty a colostomy bag for the first time:

... When the first time I empty the colostomy bag, one of the bystanders taught me how to perform it when we were at the general hospital. I didn’t know even how to release the clamp also. It felt difficult. Now I feel comfortable when doing it with that experience. .... No, not any staff member taught me how to do it.

Not only such special procedures, but some small general procedures were also challenging to perform at the beginning of the bystander’s career. One unpaid bystander explained the situation that she had to face at the beginning.

I didn’t use a bedpan before, and I didn’t know how to use it. No staff member taught me how to do it. Then I asked other bystanders how to do it. The other one is I didn’t know how to move the valve of the urine bag first. Then I asked another person who was nearby. Now I am used to doing those ...

Overall, the findings from this study highlighted that the lack of training and proper orientation influenced the bystanders’ initial stage. It was worse when it came to special and general procedures, such as emptying colostomy bags, emptying urine bags, and handling bedpans. Further, the bystanders emphasized that staff members did not teach any of those procedures at the beginning of their role as a bystander. Rather, new bystanders observed and received instruction from other bystanders in their ward
Lack of Support

The study findings indicated that most bystanders did their work by themselves. They received almost no help from anyone, especially not from staff members. Hence, they often felt a lack of support that lead to constraints and problems.

Even though the bystanders would be able to manage most caring, in some instances they needed extra support, especially when they wanted to move the patient from the bed to a wheelchair and back. One unpaid bystander explained her situation:

*I could be able to manage other things. As I told I used to look after my mother even at my home before hospitalized. So, I can manage the caring activities that need her. Anyway, sometimes managing her alone is feel difficult especially bring to the chair and transfer to the bed.*

Further, when nurses needed to send patients for tests and referrals, the bystander needed to prepare the patient and transfer the patient to a trolley or wheelchair. Transferring patients to the trolley and carrying the patient here and there inside the hospital without proper support was challenging. Lifting and transferring was even difficult for the army member who was a bystander:

*...It is difficult to control the patient alone especially when transferring to a trolley or a wheelchair from the bed and vice versa. Further, when carrying him for radiotherapy and carrying him here and there inside the hospital, I felt very challenging for me.*

Thus, some tasks needed two people, no matter how strong the individuals were.
The findings further highlighted that support staff, such as attendants, were of not much help for the bystanders. One participant pointed out that “… in general, we did not get any support from at least attendants. I have to do everything myself… do patient care alone.” One bystander pointed out that even support from nurses was not satisfactory.

... I used to do all the things alone. I do not like to call nurses. I do all that I can. It is very difficult for them as well due to their busy work. And I feel it is very difficult to tell them as well. I don’t like to get blamed. I usually only complain (to the nurse) about the patient when the patient is trying to escape from the bed. It is not comfortable to complain about everything to the nurses every time the patient asks to call nurses. .... I am not saying all of them are the same but sometimes some nurses are not used to talking smoothly. Even sometimes it is like blame...sometimes nurses do not do something, yet we are asked at once. I think they have to do many works and it may be the reason.

Hence, bystanders had to take on the routine workload in informal caregiving in the ward. They received minimum support from the hospital staff, which sometimes caused bystanders to face health hazards and put patients at risk.

**Bystander’s Fear of Approaching Nurses for Help**

The bystanders reported being afraid to go to the nurses and ask or tell them about something related to their patients. One bystander pointed out that going to the nurse with a request is “like seeing a demon.” This situation is presented in detail by an unpaid bystander as follows:
We are afraid to go and talk to the nurse because of this. Yet I do go to them. But some are very scared. It’s like seeing a demon. That is injustice for the patient. The proper interventions are not happening to the patient at the right time since the bystander is afraid to complain about the issue. In my case, my patient complains even at midnight, so when I inform the nurses, they show reluctance to respond to our complaints. Even though I tell, their support should be there for really bad patients, when the patient gets worse, they should come to the patient and see what’s wrong. Even they can ask, “what is wrong, does it hurt?” Even giving two paracetamols might have healed the patient.

This bystander considered it an injustice to the patients that proper interventions were not happening at the right time since the bystanders were afraid to complain about those issues to the nurses.

**Coping with Grief and Death**

Unpaid bystanders, who were almost always close relations or close friends of the patient, described being worried about their patients’ conditions, especially those in the end-of-life stage. One unpaid bystander who was the patient’s sister explained:

*I am worried about my sister. She is 51 years old. She is married, she doesn’t have her own kid. But she adopted a child. Her husband is not paying much concern to her. Since she is a cancer patient, she is really mentally depressed of not being recovered back. The day before yesterday she cried a lot regarding her adopted child. That made me down too by witnessing her grief.*
This bystander and others in the study described working hard to look after their patients in the ward without much physical or educational support, let alone mental health support, from health care workers, including nurses. The unpaid bystander caring for her sister highlighted a special health care team, including a nurse, that used to come and help the patients:

*Actually, there is a special place for patients who cannot be cured by giving treatments. They teach bystanders how to take care of them.*

The unpaid bystander elaborated further: “there is one place to decrease pain and one place to accept (hospice) patients, those who cannot be cured with the treatments.” It was also described by the bystander as “they come and perform and help patients to do meditation.” Just describing these extra supports seemed to enhance this bystander’s morale.

**Lack of Facilities**

Both paid and unpaid bystanders reported working at bedridden patients’ bedsides with inadequate facilities. The bystander participants highlighted many difficulties and problems due to this, which lead to many health problems. They sometimes felt that the most basic facilities were not available.

Among those facilities, many paid bystanders discussed the lack of a proper place to sleep. All beds were typically occupied by patients, and some patients even had to sleep on the floor. Hence, bystanders were not able to sleep on a bed or cot at night. They
tried to sleep close to the patient on the floor between the beds using a piece of cardboard. One bystander participant highlighted her experiences with sleeping:

*Sometimes we sit in a chair even at night. These days, due to “Corona,” there are some empty beds. So, I sleep there ... (laughs)... Some days we use cardboard. We clean the floor and sleep on the cardboard. There is dust in the ward, so we cover ourselves from top to bottom.*

The unpaid bystanders described that they mostly did not sleep on the floor. They instead sat on a chair close to the bed. One unpaid bystander explained as follows:

*I don’t sleep at all. I am scared as sometimes my mother gets an asthma attack. She is an asthmatic patient. At that time, she needs my help. So, I don’t sleep. ... I sit on the chair at the bedside.*

Further, these unpaid bystander participants highlighted the difficulty of working as a bystander for days, weeks, and even months. They felt that the lack of sleep and the heavy workload exacerbated their health conditions. Hence, some of them split shifts if they could. However, it was difficult to find an alternate person in most cases. This anecdote identified the situation and workload of the bystander that influenced splitting shifts:

*We used to change shifts every two days with my sister-in-law. Luckily, I have her. If I had to stay continuously. .... Oh...I can’t even imagine what would happen to me. It is really hard to stay continuously....it is hard to stay days and days without proper sleep. On the one hand, our mother-in-law is bedridden, and*
we need to do everything for her. On the other hand, I have hypertension too. So, it is difficult for me to be with her continuously. I will be fallen sick too.

Even among the paid bystanders, it was difficult to find a good person to split the shift if the bystander felt tired. Even if they found someone, that person was not always willing to hand back over the patient and that created problems:

*If I get a patient who doesn’t sleep at night, after two days I try to replace my role with another bystander as it is hard to be without sleep. Then I go to my boarding place and have a good bath and sleep well and come back again. ...but sometimes other (paid) bystanders refuse to hand over the patient to me again. At that time, I have to fight with them to get my chance.*

Another common issue both paid and unpaid bystanders faced was a lack of sanitary facilities. There was no separate washroom allocated for visitors or bystanders in the ward. All of them needed to go to common toilets and washrooms that were shared with the patients. One bystander highlighted this situation as “There is a risk of getting infections since all are in the ward using the same washroom and toilets.” Nearly all bystanders in the study raised this concern.

It was further identified that there was not a separate place for Muslims to pray. When the researcher asked an unpaid Muslim bystander about where they performed religious activities, he stated that he did not know of a place: “I don’t know about such a place. Maybe there is a place, I don’t know yet. I do it while sitting on the chair after having a bath. It is good if we have a separate place.” It was later determined that there was not such a designated place for prayers.
Overall, the findings of the study highlighted that, when paid and unpaid bystanders helped to care for patients, they experienced many challenges and difficulties. At the beginning of a bystander’s career, they did not receive orientation or simple training for their role. Unpaid bystanders were open in discussing challenges. Further, lack of support from health care workers, such as nurses and other support staff, and the lack of basic facilities created a situation that could put bystanders’ health at risk and affect the quality of care they provided to patients with cancer.

**Question 1D: What is the Most Difficult Thing about Being a Bystander?**

Paid and unpaid bystanders reported different issues when the researcher asked about the most difficult challenges.

**The Most Challenging Thing for Unpaid Bystanders.**

As unpaid bystanders were typically close relations of the patients, they were more concerned about their patient’s difficulties than their own. However, they described the most difficult parts of being a bystander.

The findings of the study highlighted that, due to Sri Lankan cultural influences, almost all government hospitals did not allow male bystanders to work in female wards and forbade female bystanders from working on male wards. This created situations where a man could not stay as a bystander with his wife or daughter and a woman could not stay as a bystander with her husband or son. If the family did not have someone of the same sex as the patient, they faced issues of finding a bystander to look after their loved
one. If they did not have enough money, they were not always in a position to hire a bystander. One bystander mother who traveled from another region explained:

*I can bear up all the challenges and difficulties which I have to face here but I always feel if I could stay full time with the son, I could do more for him. But due to these rules in our government hospitals, people like us are facing troubles. But in the private hospitals or even paying wards in this hospital, they have separate rooms where any person is allowed to stay. .... I received some money from some strangers who had stayed with me in the temple. They asked me to pay the bystander from that money. They were very empathic; they knew I was from a long distance away and poor. They helped me to keep a bystander for three days.*

Some unpaid bystanders felt that the most difficult thing to manage was patients who needed special procedures. One participant highlighted the difficulties and responsibilities they faced as a layperson without proper knowledge and training when looking after the patient with a tracheostomy tube:

*I remember that after surgery, medical officers placed a tube-like thing on the neck to facilitate breathing. It was a really difficult time for my son and me as well. I was quite busy at that time, so I rarely found any free time. My son didn’t sleep. He had a fever frequently. I used to remove the secretions around the tube all the time. So always I had to keep my eyes on him. I also removed the secretions around the inlet of the tube and those are coming outside using that gun like equipment.*
Other participants also faced the challenging task of managing a colostomy bag. One bystander explained:

.... emptying the colostomy bag is a most challenging task for me. It has to do very carefully. Otherwise, I have to wash the clothes of my father and even the bedsheets. So, I need more attention too. Before it too much fill I have to empty it. So, it is a big responsibility.

The findings also highlighted that, for many patients, mobilizing the patient by themselves was the most difficult thing about being a bystander. They felt it was difficult to carry the patient to different places within the ward and the hospital. The bystander participants reported several incidents that happened when mobilizing patients alone. One participant described the following incident:

*The day before yesterday, when I brought my mother to the toilet, she couldn’t stand up. We had to stay around half an hour to one hour in the bathroom.*

*However, I make her stand up and sit in the wheelchair and brought her back to the bed. ... The time was 4:00 AM. So, I didn’t call nurses or anyone. At...that time there were only two nurses. So, I didn’t call them. ... the most difficult one I ever faced...was handling the mother alone, when taking her out of the bed is the most challenging task for me. I am afraid whether she will fall down.*

A similar incident regarding mobilizing the patient alone within the hospital was described by another participant.

*... carrying the patient here and there within the hospital alone is the hardest time for me. Especially when I bring the patient for the clinic or radiotherapy, I must*
face such difficulty. Mostly I request help from the hospital support staff but it is also difficult to find one sometimes.

Accordingly, unpaid bystanders reported several of the most difficult things about being a bystander, including the rules requiring same-sex bystanders, the need to look after patients who required special care, such as tracheostomy care and colostomy care, and mobilizing the patient alone within the ward and the hospital.

The Most Challenging Thing for Paid Bystanders.

The most difficult challenges were also described by paid bystanders. As paid bystanders mostly had experience with informal care, they were more concerned about their personal difficulties rather than patient-related challenges.

The paid bystanders reported a lack of proper sleep as the most difficult thing about their jobs. Paid bystanders were especially worried about being able to continue their work due to side effects from sleepless nights, such as headaches:

Some patients do not sleep a whole night. Some cry, some yell...I usually use a mat and sleep on the floor close to the patient’s bed. But when this (crying and screaming) happens it is very difficult to get a good sleep. So, I keep a chair and stay with the patient and keep asking “what’s wrong?” I provide a sip of water if needed. This nocturnal awakening causes us to feel much difficulty the next day when working. I feel so sleepy and have a headache on the following day, too.

Some paid bystanders who were independent workers reported that hospital support staff bully them. One paid bystander highlighted one incident she had to face:
There is an old attendant who continuously bullies me and causes me trouble. Once she tried to make me lose my job. It’s all due to the jealously of earning more money than the agency-recruited bystanders. We make Rs. 2000 rupees but agency people get Rs. 1500 as they have to give Rs. 500 to the agency.

The findings of the study further highlighted that the most difficult challenge for paid bystanders was to get enough work shifts. One paid bystander described the situation as follows:

In some wards, some bystanders have been working for 10-15 years as bystanders. So, they are very familiar with the staff and others. Maybe thus, there is an issue that we get patients only when they all have patients to look after unless the people in the ward don’t inform us about the vacancies of bystanders. There we have to shift to another ward to find patients. So, we have problems finding patients. Some wards such as X, Y, Z... We can’t even go.

As a coping mechanism for these challenges, one paid bystander described forming a team of independent bystander colleagues who helped each other. Within this team, they mutually cared for patients and referred patients to other colleagues. One paid bystander elaborated on how this happens:

I can’t do all the patients at the same time. What I do is work collaboratively with my friends. I and my bystander friends have made a team including 5 to 6 people. Once my friend is taking care of a patient, she asks me to come around. Then that particular patient gets to be friends with me. It happens the other way around, too. So that way, if I am not there at the moment in the hospital, my friend can
take care of the patient. So that won’t be a problem. We equally distribute the patients that we take care of among the team members and settle the (pay for them) work.

The findings showed that the most difficult thing about being a paid bystander were sleepless nights and their effects, incidents of bullying, and the monopoly bystanders have on access to paying patients in some wards. To overcome this monopoly, independently paid bystanders formed an unofficial collaborative group to mutually allocate patients based on the requests received.

This section explored research question one, which focused on the bystanders’ perspectives on providing informal care for bedridden patients with cancer in hospital settings in Sri Lanka. It also explored how people became bystanders, the things they did to help take care of the patients, the challenges or difficulties they experienced when caregiving, and the most difficult parts of being a bystander. Paid and unpaid bystanders worked at the cancer hospital and looked after bedridden cancer patients who needed palliative care. Unpaid bystanders faced these barriers while caring for their hospitalized patients. However, paid bystanders continually faced these challenges.

**Research Question Two – Bystanders’ Interactions with Nurses**

Research question two for this study is “What are the types of interactions bystanders have with nurses?” Initially, there were two qualitative interview questions for this research question, as follows:
**Question 2A:** Please tell me about the times you have interacted with the nurses. When have you needed to get help from a nurse?

**Question 2B:** Can you tell me what happens when you ask for help from a nurse? How do the nurses respond to your requests?

The researcher later identified that these questions could be combined; the research findings are delineated below.

**Bystanders’ Reluctance to Interact with Nurses**

Study findings revealed that many bystanders described that they worked alone. They reported not having much interaction with the nurses in the ward. One paid bystander said, “I didn’t come across any situation to ask help from nurses.” Another unpaid bystander confirmed this statement: “Actually, I didn’t face such a situation so far. I do manage the things by myself.” Both paid and unpaid bystanders preferred to work alone and had minimal interaction with the nurses.

Further, paid bystanders stated they did not want help from nurses. One of the paid bystanders explained it as follows:

*Actually, I do not need to get help from the nurses. Now I can do all the caring activities by myself. However, if I need to make any complaints on behalf of the patient regarding his or her condition, I used to contact them.*

The findings pointed out that bystanders did not like to interact with or call the nurses, assuming they were busy. Further, some bystanders felt that it was difficult to
interact with nurses because they, the bystanders, would get blamed. This situation was highlighted by a paid bystander:

*I do all the things alone. I do not like to call the nurses. I do all that I can. It is very difficult for them as well due to their busy work. And it is very difficult to tell them as well. I don’t like to get blamed. I usually complain about the patient when the patient is trying to escape from the bed. It is not comfortable to complain about it to the nurses every time once the patient asks to call nurses.*

Citing that nurses are busy, difficult to talk with, or likely to assign blame, the bystanders reported working alone as much as possible rather than interacting with the nurses. Both paid and unpaid bystanders described managing all caring activities by themselves.

**Help from the Nurses**

However, some bystanders in the study did mention instances during which the bystanders sought help from the nurses. One unpaid bystander described it as follows:

*Nurses are generally helpful to us. For example, if I complain about my mother suffering from severe pain, they come quickly and give some pain killers if possible. Otherwise, they call the doctors and get their advice or opinions, even at midnight.*

*Another paid bystander described how nurses helped to manage his patient’s pain.*
He explained how nurses provided a pain medication prescribed for when the pain got worse:

*Actually, when we inform them that the patient is screaming with pain or any complaint, they come and observe and provide the pain medications since it is prescribed in the file. The tablets or injections are prescribed to be given at the worst pain.*

The study findings further pointed out that most bystanders described being satisfied with the nurses’ support. One unpaid bystander further elaborated as it related to her mother:

*They used to help us. If I say that my mother complains about abdominal pain, nurses give pain killers. If the need to, nurses inform the doctors. They frequently come and measure blood sugar level, too. If it is low, they ask me to make tea with sugar and offer it to the mother. And they used to come again and check after some time. Therefore, I can say they are good.*

Bystanders also described how nurses’ help was extended in other instances. For example, nurses guided one of the paid bystanders to become an independent rather than being an agency employee:

*When I was working in the same ward over and over again, the nurses said “Why are you working so hard and yet paying the agencies? You can work alone and earn. You can come as a private/independent bystander. You can stay in the ward.” With that invitation, I left the agency and started work as an independent bystander.*
Another example highlighted that nurses and some ward doctors were helpful to the bystanders, especially when they became sick while working. A paid bystander described such a situation as follows:

_Sometimes I get a headache once or twice a month. At that time nurses say that “You are not eating properly; you have worsened gastritis.” And they give Digene syrup and Panadol. Our ward doctors are also very good; if our problems were not relieved, they write us a chit (prescription) on our request. The medications will be around 300 rupees. Once I used them three times the problem would be relieved. We don’t go to private channeling centers for 700-800 rupees. Our ward doctors help us._

It was beyond the scope of this study to identify how frequently doctors provided such prescriptions.

**Bystanders’ Requests and Nurses’ Advice**

Even though the bystanders were used to working alone or independently, there were instances when they had to interact with nurses to get advice. Many unpaid bystanders mentioned interacting with nurses to get information about the patient's condition and advice regarding the patient’s needs. One unpaid bystander described how she interacted with nurses to get information and advice about her son:

_If I want to ask something...like my son’s condition or the progress, and what are the things I need to bring for the feed as my son has the tube for feeding, I used to go and ask from the nurses._
Bystanders described how some nurses’ advice seemed like orders or instructions. One unpaid bystander highlighted such a situation when she was instructed to ensure that someone was continually with her son after surgery:

_Hmm…sometimes if nurses wanted to give an order or message, they used to call me and say like “Amma (Mother), you have to keep someone full-time with your son after the surgery, as he cannot do things alone after the surgery.”_

Another unpaid bystander explained:

_In some instances, especially at the beginning of the hospitalization, they used to advise a little loud… I was not able to stay in the ward after visiting hours. Now they know my situation. Hence, they are not much influence if I am a little late leaving the ward._

If bystanders needed to get advice from nurses, they described going to the nurses to deliver their communication. Further, the bystanders said that when nurses needed to give advice or instructions, they came to the bystanders and delivered their communication.

**The Influences of Nurses’ Workload for Interactions**

Although bystanders responded that nurses gave help and advice when the bystanders informed them of patient complaints, some bystanders described occasions when nurses delayed responding to such requests. One unpaid bystander explained:

_Yes... nurses respond. It depends on the person and also the time. Some will respond quickly, and some may take time to come. Some may say... “Okay you_
can go now I will come and see your son.” But it would take time, or some would forget. May be due to their heavy workload.

Another paid bystander stressed that it might have been due to a shortage of nurses and a high number of patients in the ward.

..... Sometimes they are busy. Somehow if they have free time, they used to help us.

Since the number of nurses is less and the number of patients is comparatively high in the ward, sometimes, nurses haven’t enough time to help us.

Further, one of the unpaid bystanders explained the importance of putting nurses’ loud or angry voices in context:

...most of the time nurses are very busy in the ward. So, we have to understand their situation too...Sometimes they may be late to respond and some nurses may respond loudly...But in general, they are helpful. They are helpful to me too.

The paid bystanders felt reluctant to call on nurses for help. One paid bystander said:

I feel it is not possible to ask for their help because already they have lots of work. So normally I don’t ask for their help as there is a lot of work already on their hands. Usually, if I need support I ask from another fellow bystander. If I don't need any support, I will do it myself, even climbing onto the bed if I am to turn the patient over. So, I don’t ask for help from nurses.

Both paid and unpaid bystanders expressed that nurses not only were not in a position to help them as soon as requested but that they often responded with a harsh
voice or “shouting.” All study participants described being ambivalent about asking nurses for help.

**Information and Assistance from Nurses**

Bystanders described some occasions when nurses helped to educate them. One unpaid bystander explained how one nurse taught her about tube feeding:

*There were some instances nurses used to come to me and talk. After my son’s surgery, one day one nurse taught me how to feed via the tube, how much I have to feed, and how I need to prepare the feed, etc.*

Another unpaid bystander also explained that a nurse educated her about the tube feeding procedure as she completed her duties in the ward:

*I can remember one nurse helped me to feed via a tube. She taught me that procedure step by step by demonstrating how to do it. So... I think they do what they can while they were doing their routine works.*

Another unpaid bystander reported being educated by a nurse regarding handling patients in bed:

*I can remember at one instance when I try to turn my mother as she can’t turn by herself, one nurse came to me and help me to turn and position her. She taught me the proper way to do it while helping me as well.*

Therefore, findings from this study demonstrated that bystander and nurse interactions included education related to informal caring and assistance, especially educating unpaid bystanders in proper care procedures.
Bystanders highlighted that they were reluctant to interact with nurses because the nurses were busy, difficult to talk with, and would blame the bystanders. However, if bystanders needed help regarding managing patient pain and discomfort, they did contact nurses and described the nurses as helpful in those situations.

**Research Question Three – Bystanders’ Recommendations**

Research question three of this study was “What are the recommendations of bystanders to improve informal care for bedridden patients with cancer in hospital settings in Sri Lanka?” Two qualitative interview questions were developed to answer this research question:

**Question 3A:** What do you recommend for improving the situation for people who are bystanders?

**Question 3B:** What things could the hospital or the national government do to make bystander care easier to provide?

The findings of research question three are combined below because the interview questions were closely related. The bystanders’ recommendations were linked with the strategies proposed for hospitals and the national government to improve bystanders’ situation and to make their jobs safer and more manageable.
Recommended to Have a Bystander and Their Service

Bystanders highlighted the importance of their service regarding inpatient care. They recommended having a bystander for every bedridden patient who cannot move or make their own decisions. One bystander explained:

*I think caring for a bedridden patient is much more needed than for a mobile patient. Suppose even a patient with dementia, if she or he forgets and tries to move from the bed, resulting in a fall. So, it is very important to have a bystander for each patient who cannot do their (self-care) work alone.*

The findings further highlighted not only the need for a bystander but also the need for proper acceptance of bystanders and their work. One paid bystander stated that the government and the health ministry need to accept bystanders’ service and take steps to regularize the role:

*I think we are not accepted anywhere. That’s why no one thinks about us. So, I think, first of all, the government health ministry needs to accept our service and need to do something to regularize our service. I do not know how to do it. But it needs to be done somehow.*

Currently, there are traditional rules and regulations in public health care facilities in Sri Lanka, such as the requirement for same-sex wards. One bystander recommended dismantling these barriers because she was prevented from staying with and caring for her son due to this rule. She further pointed out that if this had been allowed, it would have saved her money and would have enhanced the care of her loved one. Hence, she suggested the government consider changing the policy:
...it is needed to give a chance to a person to stay with the patient if he or she is not the same sex. Especially if the mother cannot stay with the son, it is not fair. I know sometimes in children wards’ it is allowed. My son is more than 18 but still, I am looking after him. Anyway, if they allow any family member to be with the patient, patients can get better caring. I think if we can do it, many families who do not have a person of the same sex to stay with the patient, it will be a benefit. Further, it is good for the wallet as well as gives quality care for the patients in the hospital. ...The hospital or the government can change its existing policies and allow any family member, relation, or friend to stay with the patient if needed without considering their sex. As I said, it will be a good advantage for the patient and the family.

Study findings further highlighted the need to develop a system for a formal bystander/informal caregiver service. One unpaid bystander pointed out the importance of such a system, including the shift-changing system.

I think if there is a system to change the bystanders' shifts like what we are doing...we do not need (extra) facilities as we can go home and... have a good sleep, bathe, etc. But there are so many restrictions to do so (in the hospital). Some families haven’t enough members to do it. Some are coming from remote areas. Paid bystanders also haven’t such a system. So, the government can think about the proper informal caring system. I think it will be good for everyone.

These findings recommended having a bystander for every patient who is bedridden and cannot do things alone. It was also recommended that the ministry of
health and the government officially accept and support paid bystander services. In addition, to enhance unpaid bystander service for families, the findings recommended ending the practice of gender segregation in the clinical setting.

**Recommended to Stop Bullying and the Monopoly Against the Bystanders**

The research findings uncovered that paid bystanders are divided into two subgroups: agency and independent. Agency bystanders were somewhat protected by their agencies, but no organizations protected independently paid bystanders, who had to face bullying and a monopoly on access to patients/clients by some agency bystanders.

An independently paid bystander said:

*There should be a mechanism for the director or the government authorities to involve and uplift our service. As we do not belong to any category, our service is neglected, and our problems of bullying and monopoly of some agency bystanders remain. However, there are some informal meetings with the agency people and us with the director if something happens or any complaints are received by the director. He used to ask to disclose the problem we have, but there was no proper mechanism to solve our problem. If any problem occurs to bystanders who come from an agency, the agency owner tries to protect them. I think we individual careers also need an organization to represent us. At least to take the responsibilities... That’s what I can recommend.*
One bystander believed that bullying was due to jealousy because independent bystanders earned more money than agency bystanders. She further recommended involving the ministry of health to solve such problems:

There was an old attendant who was continuously bullying me and causing me trouble. Once she tried to make me lose my job. It’s all due to the jealousy of earning some money more than the agency recruited bystanders. ... Those issues were not seen by the ministry. It should be looking at the ministry level.

Some of the paid bystanders were more experienced and had worked for a long time in particular wards in the cancer hospital. They had a strong relationship with the ward staff. They used their monopoly to look after as many patients as possible in that ward. Other bystanders were given limited access or not allowed to work in these wards. One bystander explained:

In some wards, some bystanders have been working for 10-15 years, so they are very familiar with the staff and others. There is an issue that we get patients only when they all have patients to look after. Otherwise, the people in the ward don’t inform us about the vacancies of bystanders. Therefore, we have to shift to another ward to find patients. So, we have problems finding patients.

In another example, that same bystander looked after several patients at the same time and allocated new patients only among her friends. The participating bystander suggested having a proper mechanism to avoid such favoritism:

There is a bystander who has been working for eight years in ward X. She is handling patients there. She asks that only other bystanders with whom she
prefers work be allowed into that ward. Also, some bystanders take care of several patients in the same ward at the same time. It happens in ward Y too. In ward Z, the staff doesn’t allow us to come. They only allow one of the family members or relatives to stay with patients. So, there should be a proper mechanism to avoid such incidents as there is no accepted practice or regulatory body in the hospital to handle or interfere with these things.

Overall, these findings highlighted the need to address unacceptable practices, identify a proper mechanism to avoid such incidents, and to identify a regulatory body in the hospital or government to handle or deal with such incidents.

**Recommended to Have Basic Facilities**

Both paid and unpaid bystanders revealed that they had limited facilities to perform their role in the ward. They reported having no places to stay and sleep, no adequate sanitary facilities, no quality foods, and not enough staff to get support.

**Need a Proper Place for Bystanders**

The findings from the study demonstrated the need for a designated place for bystanders. Bystanders usually stayed on a chair close to the patient’s bed. However, in hall-type wards, the beds lined the hall and there was limited space between them. The bystanders needed to use that space to stay with the patient. However, that space was also needed for health care workers if they needed to treat or care for the patients:
Sometimes, we find that even bystanders like us don’t have a proper place to stay with the patient. The space between the two beds is much less, like one meter.

Space is there for nurses to do the treatments and care. Anyway, we don’t expect that much from the hospital since there is a very large number of patients. At the same time, we have to think about our services too... So at least it is good to have enough space for us.

The unpaid bystander also discussed needing a place to stay overnight within the hospital. The mother of a patient/son from a rural area recommended having a common lodging area available within the hospital for a nominal fee:

At least if I can’t look after my son full-time in the ward, there should be a place to stay within the hospital premises or close to the hospital. It will also very useful and safe for us. It is okay if they make some money for that.

Need Facilities to Sleep

All bystanders emphasized that there was also no proper place to sleep due to the limited space between beds. They could not go somewhere else to sleep because they needed to be with the patient:

...if we don’t have enough sleep, we won’t be able to accomplish the next day's tasks. That’s why I usually try to get at least a two-hour sleep. We have to be there with the patient all the time since nurses ask for us to distribute the medications to the patients. They ask, “Who is taking care of this patient?”
Hence, we cannot even go and find a different place to sleep. We have to be with the patient.

The bystanders further stated that if they had a bed or cot, they could at least sleep for a couple of hours:

*It is better if we have a small bed. Then we can sleep at least for around two hours. Even we know it may difficult. Otherwise what happens when we sit all day? Our legs will be swollen. It has happened to me too, but it soon is relieved, and we get used to it.*

**Need Proper Sanitary Facilities**

The bystanders were required to use the common toilets and the bathrooms alongside the patients; these facilities were not adequately cleaned. They described having no separate toilets or bathrooms for bystanders or even for visitors within the ward. All bystanders described being concerned about their health. Some paid bystanders reported going to a nearby boarding place to use the toilets and bathrooms, but unpaid bystanders had no such choice. One paid bystander explained:

*We have bathrooms, but those are the patients’ common bathrooms. It is difficult to use the same common toilets and bathrooms. Sometimes we go to the boarding place and fulfill the needs. Or otherwise, we have to wash very well before going to the washrooms. We clean by using ‘Dettol’ before going to the washrooms. They are very unclean. We are afraid of the germs. If we are not careful, we also*
get germs. If you or someone can improve or suggest having a separate toilet and bathroom. At least one common facility for all bystanders in the ward is needed.

One bystander suggested including the necessary basic facilities in future construction plans:

As I suggested, the hospital or the government can think about developing our facilities such as extra beds, separate toilets, bathrooms, etc. I think if the government allocates money, the hospital director can do the arrangement. I know with the limited facilities in government hospitals it may difficult. Even when they plan new buildings for the wards, they can think about us.

Need Quality Foods

The bystanders reported not being allowed to get free food from the hospital. Hence, some of them used the canteen to buy food. It was expensive and there were no fresh fruits available. One bystander suggested addressing those issues:

Hmm…One more thing... We bought everything from the hospital canteen. They are quite expensive. Also, fruits are not available there. There is a place we can buy things outside of the hospital. But unfortunately, it has been closed due to the coronavirus crisis. Moreover, visitors also don’t have permission to come. That’s why we have to face this problem. So, I think it’s better to serve foods for bystanders along with the patients. But I must say, some days we receive food when there is a lower number of patients in the ward. The excess foods are distributed among us. Most of the time I used to buy food from the canteen. I serve
the meals bought from the canteen to my son and I eat what is given from the hospital. Meanwhile, paid bystanders always get priority when food is distributed among us. As they are familiar with the hospital staff more than us. ... That's also an issue that needs to be addressed.

Unpaid bystanders highlighted the need to support paid and unpaid bystanders equally. The availability, taste, and nutritional value of foods in the hospital was considered inappropriate. One unpaid bystander further worried about the way foods were served and distributed in the ward and recommended taking action to address these issues:

Actually, foods that are given by the hospital are not delicious. I think the nutritional status of patients is important to speed the recovery too. It is better to give delicious and nutritious foods. ...I think the preparation of the foods, I mean cooking, is not good quality and results in bad tasting food. Further, distributing and offering foods to the patients is not appropriate and not attractive due to old trolleys, aluminum pots, etc., and harsh behavior of the staff that needs to be corrected.

More Staff Need to Help

The bystanders felt that the number of nurses and support staff were not adequate in the ward. One unpaid bystander recommended increasing the number of nurses and the support staff due to their heavy workload:
... it is better to have more nurses and other helpers in the ward. There are only 5-6 nurses in a shift...but more than 60 patients most of the time. It is quite difficult to perform everything by themselves. The thing is while they were carrying their usual assigned duties, they haven’t time to pay attention to our problems. In that case, we also cannot ask for any help from them. I feel that it is not fair to ask help from them when they seem to be busy.

The same unpaid bystander recommended accepting that the bystander service would help address the shortage of nurses in Sri Lanka:

I heard that there is a nursing shortage in the country. They have to do more to increase the nursing workforce too. At the same time, the government can think about formalizing the bystander service as an acceptable service in Sri Lanka. In that way, patients can get more quality care and it may be one answer to the problem of shortage of nurses in Sri Lanka.

In this demanding situation, bystanders noted that some staff members shouted at patients and bystanders. One unpaid bystander explained the situation and recommended changing such behavior:

I must say some attendants/supportive staff are shouting at patients and bystanders. Patients are psychologically depressed as a result of their disease condition. So, when attendants begin to shout at them, patients feel really bad. Sometimes attendants think pulling a trolly is a burden to them. So, it is difficult to get their help. There is also no proper place to complain about them. However, they belong to the hospital staff. So, this behavior should be changed.
Overall, the findings highlighted that bystanders have minimum facilities for informal caregiving. They did not have a proper place to stay and sleep, adequate sanitary facilities, quality foods, and enough staff to get support. Hence, all bystanders recommended taking the necessary actions to address those issues and improve their basic facilities.

**Recommendation to Have Basic Training**

Both paid and unpaid bystanders recommended having at least basic training regarding informal care since most bystanders have no training. Some paid bystanders have experience with caring, but most unpaid bystanders are looking after their loved ones for the first time in their lives and have no experience in this area. One of the unpaid bystanders recommended having basic training as follows:

> ... if we can have small training or they could teach us about the essential basic procedures to look after our patients, it would be very good. Especially people like us...I mean family members, relations, or friends who are coming for the first time to look after their patients and do not know those things.

Further, the same unpaid bystander suggested that the basic training could be given through the nursing staff, based on her experience:

> I think it is good if nurses can teach us how to do proper care if possible. As an example, now I know very well how to prepare food and give it when patients have a tube. as one nurse has taught it to me. Especially people like us don’t know those things.
Hence, a proper system to teach or impart simple knowledge should be developed especially to unpaid bystanders, but also to paid bystanders in inpatient care. Another bystander also highlighted the importance, as follows:

*When we are experiencing the duties of bystanders, most of the things are new to us. We have to ask others to learn. If there is a proper system to teach or give simple knowledge to us in inpatient care, at least someone can give a brief introduction that also is enough. It is very valuable.*

Concerns about possibly harming the patient were expressed by a paid bystander who recommended the need for caregiver education:

*Bystanders who do not know to do the things properly, it would harm the patient. So, my suggestion is that if someone wants to be a bystander, they should be trained at least for one week. Sometimes the bedridden patients are there. They should be managed properly. Inexperienced ones would harm the patient and may cause more pain. These things should be conveyed and are needed to teach to the bystanders.*

Although several paid bystanders in the study had many years of experience in caring, they had no formal training in informal care. Therefore, at least basic training in informal caregiving was recommended by both paid and unpaid bystanders.

This section addressed research question three, “What are the recommendations of bystanders to improve informal care for bedridden patients with cancer in hospital settings in Sri Lanka?” The findings highlighted many recommendations to develop the bystander service to improve the informal care of bedridden patients with cancer in the
cancer hospital settings in Sri Lanka. It was recommended to have a bystander for every bedridden patient, accept the bystander service, stop bullying and the monopoly among bystanders, and have basic facilities, including a proper place for bystanders to stay and sleep, adequate sanitary facilities, quality foods, and enough staff to provide support in the caring process. Further, both paid and unpaid bystanders recommended having at least basic training regarding informal caregiving, since almost all have not had proper training.

Most of the bystanders expressed that the hospital director should be involved in solving their problems, as bystanders who work in the cancer hospital were aware that care was under the purview of the hospital director. Although some of the paid bystanders had an informal agency to look after them to some extent, there was no such organization for the independent bystanders. Hence, they also expressed the desire to have a union to protect them.

The bystanders’ recommendations also indicated that government-level policies need to be created, with the goal of developing the bystander service and helping to address the dearth of patient care.
CHAPTER 5
DISCUSSION, IMPLICATIONS, AND CONCLUSION

This qualitative descriptive study identified bystanders’ perspectives on their provision of informal, hospital-based care to bedridden patients with cancer in Sri Lanka. In this chapter, the major findings related to the three research questions will be addressed. These findings include the bystanders' perspectives on providing informal care for bedridden patients with cancer in hospital settings in Sri Lanka, the types of interactions bystanders had with nurses, and the recommendations of bystanders to improve informal care. The discussion of these study findings will be followed by clinical, research, and policy implications, and an overall conclusion of the study.

Summary of Study Findings

The summary of the study findings is presented under each research question. The findings of the research questions were summarized under the bystanders’ perspectives, the bystanders’ interactions with nurses, and the bystanders’ recommendations.

Research Question One – Bystanders’ Perspectives

Research question one of this study is “What are the bystanders' perspectives on providing informal care for bedridden patients with cancer in hospital settings in Sri Lanka?” The findings for this question are summarized according to the following four qualitative interview questions.
Question 1A: Please Tell Me How You Became a Bystander

The study identified two main types of bystanders: unpaid and paid. Although their care tasks as bystanders are similar whether they are paid or unpaid, the reasons why and the way they became bystanders were different.

Unpaid bystanders had no initial intention to become bystanders. They were usually close relatives, such as mothers, fathers, daughters, sons, sisters, brothers, and daughters-in-law, or close friends of patients with cancer. They needed to look after their loved ones, so they became bystanders. Hence, they had no intention to work for money. Most unpaid bystanders are dedicated to this role, sometimes ignoring their other family commitments, such as employment and caring for other relatives. They view looking after their loved ones as their responsibility.

One unpaid bystander represented the Sri Lanka Army. It was a unique situation that was identified in this study. It was found that Sri Lankan military forces have a mechanism to assign a person as a bystander when a member of the forces is severely ill and/or bedridden.

Paid bystanders choose to take on the bystander role. They highlighted many reasons for choosing this employment, including their initial intention to become a bystander, dissatisfaction with previous work, and an interest in making more money. However, in the Sri Lankan context, the bystander is not an officially recognized job and therefore there is no security for this job. Overall, the paid bystanders were worried about this.
Question 1B: Please Tell Me All the Various Things You Do to Help Take Care of the Patient

Study findings identified the various care tasks that bystanders provided to hospitalized patients with cancer. These tasks were organized by morning, noon/afternoon, and evening routines. Each routine includes basic care tasks and special procedures that some bystanders need to provide. These findings are summarized in Table 5.1 and Table 5.2.

Table 5.1 Bystanders’ Morning Routine with Special Procedures

<table>
<thead>
<tr>
<th>Normal Routine</th>
<th>Special Procedures</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Wake up early in the morning and engage with basic patient cleaning activities, such as,</td>
<td>- During the same time, bystanders attend to special procedures such as,</td>
</tr>
<tr>
<td>- washing the face and the body,</td>
<td>- offering bedpans and urinals,</td>
</tr>
<tr>
<td>- brushing the teeth,</td>
<td>- cleaning bedpans,</td>
</tr>
<tr>
<td>- changing diapers,</td>
<td>- emptying urine bags,</td>
</tr>
<tr>
<td>- cleaning the perineal area,</td>
<td>- emptying colostomy bags,</td>
</tr>
<tr>
<td>- giving pressure point care,</td>
<td>- engaging in tracheostomy care,</td>
</tr>
<tr>
<td>- changing clothes,</td>
<td>- charting urine output, and</td>
</tr>
<tr>
<td>- keeping the patient comfortable on the bed.</td>
<td>- applying temporary dressing to bedsores, if available.</td>
</tr>
<tr>
<td>- Offer breakfast and oral medications around 8.00am and allow the patient to rest until tea around 10 AM.</td>
<td>- For patients who cannot eat, bystanders feed them via feeding tubes.</td>
</tr>
<tr>
<td>- Offer a cup of tea with biscuits.</td>
<td></td>
</tr>
<tr>
<td>- After tea, let the patients rest again. Some bystanders talk and listen to the patients during this time.</td>
<td></td>
</tr>
</tbody>
</table>
Table 5.2 Bystanders’ Noon and Afternoon Routine with Special Procedures

<table>
<thead>
<tr>
<th>Normal Routine</th>
<th>Special Procedures</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Offer lunch.</td>
<td>- For patients who cannot eat, bystanders feed them via feeding tubes.</td>
</tr>
<tr>
<td>- Offer oral medications around 2.00pm</td>
<td>- Parallel with these, repeat special procedures, such as,</td>
</tr>
<tr>
<td>- Give evening care, including,</td>
<td></td>
</tr>
<tr>
<td>- changing diapers,</td>
<td></td>
</tr>
<tr>
<td>- changing clothes,</td>
<td></td>
</tr>
<tr>
<td>- caring for pressure points,</td>
<td></td>
</tr>
<tr>
<td>- turning the patient,</td>
<td></td>
</tr>
<tr>
<td>- giving a bath,</td>
<td></td>
</tr>
<tr>
<td>- keeping patient comfortable on the bed, and</td>
<td></td>
</tr>
<tr>
<td>- offering evening tea with biscuits around 3 PM.</td>
<td></td>
</tr>
</tbody>
</table>

When patients go to sleep at night, most paid bystanders report sleeping on the floor and unpaid bystanders report staying close to the patient’s bedside on a chair to attend to the patient’s requests during the night. Evening and night tasks and special procedures are detailed in Table 5.3.

Table 5.3 Bystanders’ Evening and Night Routines with Special Procedures

<table>
<thead>
<tr>
<th>Normal Routine</th>
<th>Special Procedures</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Offer early dinner.</td>
<td>- For patients who cannot eat, bystanders feed them via feeding tubes.</td>
</tr>
<tr>
<td>- Offer oral medications around 8 PM.</td>
<td>- Parallel with these, repeat special procedures at night, such as,</td>
</tr>
<tr>
<td>- Attend to night care, such as,</td>
<td></td>
</tr>
<tr>
<td>- changing diapers,</td>
<td></td>
</tr>
<tr>
<td>- changing clothes,</td>
<td></td>
</tr>
<tr>
<td>- caring for pressure points,</td>
<td></td>
</tr>
<tr>
<td>- turning the patient,</td>
<td></td>
</tr>
<tr>
<td>- giving a shower or bath,</td>
<td></td>
</tr>
<tr>
<td>- keeping patient comfortable for sleep,</td>
<td></td>
</tr>
<tr>
<td>- offering night tea with biscuits around 9 or 10 PM.</td>
<td></td>
</tr>
</tbody>
</table>
Apart from these routine tasks, some days the bystanders had to bring patients to different units in the hospital for tests, radiotherapy treatments, and to get expert opinions. This required more patient handling, such as transferring the patient from the bed to a wheelchair or trolley.

**Question 1C: When You are Helping to Care for the Patient, What are the Challenges or Difficulties You Experience?**

This interview question identified the findings related to the challenges and difficulties faced by bystanders while they were engaged in the caring process described in the above section. While both unpaid and paid bystanders engaged with informal caregiving for bedridden patients with cancer around the clock, some of them faced various challenges. The main challenges and difficulties identified include a) lack of proper training about essential caring activities, including special care activities, such as emptying urine bags, and colostomy bags; b) lack of support from hospital staff, including nurses; and c) lack of basic facilities in and around the ward, such as a proper place to sleep, a proper place at the bedside to stay with the patients, and adequate sanitary facilities, such as separate washrooms. Bystander challenges and difficulties are reported in Table 5.4.
Table 5.4 The Challenges and Most Difficult Things Faced by the Bystanders

<table>
<thead>
<tr>
<th>Challenges or difficulties faced by the bystanders</th>
<th>Most difficult things about being a bystander</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Lack of proper training about essential caring activities, including special care activities, such as emptying urine and colostomy bags and tracheostomy care</td>
<td>• Finding a same-sex caregiver/bystander</td>
</tr>
<tr>
<td>• Lack of support from hospital staff, including nurses</td>
<td>• Managing patients who need special attention due to various procedures, such as patients with tracheostomy and colostomy</td>
</tr>
<tr>
<td>• Lack of basic facilities in and around the ward, including</td>
<td>• Positioning and transferring patients</td>
</tr>
<tr>
<td>- a proper place to sleep,</td>
<td>• Not getting proper sleep, which leads to health issues, such as headaches and swollen legs</td>
</tr>
<tr>
<td>- a proper place at the bedside to stay with the patients, and</td>
<td></td>
</tr>
<tr>
<td>- adequate sanitary facilities, such as separate toilets and washrooms.</td>
<td></td>
</tr>
</tbody>
</table>

The following are the most difficult things for paid bystanders:
• Bullying by some health care support workers
• Monopoly by paid bystanders who do not allow colleague bystanders to work in some wards

These findings showed that bystanders engaged with many informal care activities for bedridden cancer patients in the hospital without even having access to basic facilities. They further indicated that bystanders have experienced many challenges or difficulties within their role.

**Question 1D: What is the Most Difficult Thing about Being a Bystander?**

Both paid and unpaid bystanders reported different things as the most difficult challenges they face in informal caregiving. The study findings indicated that unpaid and paid bystanders reported similar topics for the most difficult challenges.
The most difficult challenges faced by unpaid bystanders included a) difficulty in finding a same-sex caregiver/bystander within the family; b) managing patients who need special attention due to various procedures, such as tracheostomy and colostomy; c) positioning and transferring patients; d) lack of proper sleep, leading to health issues such as headaches and swollen legs; e) bullying by some unsupportive health care workers; and f) competition among paid bystanders. The most difficult challenges are described in Table 5.4.

Overall, unpaid and paid bystanders explored how they became bystanders, their perspective on informal caregiving around the clock, and the challenges they face. The study provided bystanders’ perspectives on caregiving for bedridden patients with cancer in the cancer hospital.

**Research Question Two – Bystanders’ Interactions with Nurses**

Research question two of this study is “What are the types of interactions bystanders have with nurses?” The findings highlighted bystanders’ reluctance to interact with nurses. Bystanders reported concerns that nurses are busy, difficult to talk with, and may blame the bystanders. Hence, many bystanders described working alone as much as possible rather than interacting with nurses.

However, when bystanders needed help from nurses, they did not hesitate to request help mostly for patients’ complaints about pain and other discomforts. Further, bystanders reported some instances of nurses helping them with their own symptoms and with employment opportunities for paid bystanders.
There were instances when the bystanders needed to get advice from nurses, and when nurses needed to give instructions or advice to bystanders. However, those communications were not always easy and smooth because nurses were not always friendly, especially with the unpaid bystanders.

Bystanders reported that, on some occasions, nurses educated and assisted them, especially if the bystander needed special training for some procedures related to care such as feeding and positioning. Interactions with nurses were undertaken by both unpaid and paid bystanders with the proper understanding of and respect about the nursing shortage, their heavy workload, and a large number of patients in the ward, all of which leads to a busy environment for nurses. However, some bystanders did not accept the nurses’ behavior; they consequently had fewer interactions with nurses.

**Research Question Three – Bystanders’ Recommendations**

Research question three for this study is “What are the recommendations of bystanders to improve informal care for bedridden patients with cancer in hospital settings in Sri Lanka?” It was answered using two qualitative interview questions. However, the findings are presented here are based on combining the two interview questions together due to their close relationship.

The findings indicate that bystanders themselves value having a bystander for every bedridden patient; bystanders believe that their service needs to be accepted by the government. Bystanders further recommend finding ways to stop bullying, harsh communication, and economic monopoly among paid bystanders. The bystanders also
recommended having basic facilities, such as a proper place to stay at the patients’ bedsides, a proper place to sleep, adequate sanitary facilities, quality foods, and enough staff to get support in the caring process. Both paid and unpaid bystanders further recommend that all bystanders receive at least basic education and training related to informal caregiving for hospitalized patients with cancer.

These recommendations from bystanders were pertinent to the hospital level. Hence, they always emphasized that the hospital director should be involved in implementing their suggestions and recommendations. Many assumed the hospital director could be involved in their issues. However, some bystanders identified that the government or the ministry of health needs to develop policies about acceptable bystander service, securing employment, and supporting their delivery of quality informal care.

**Socio-ecological Model as the Theoretical Framework**

The socio-ecological model was used in this study as the theoretical framework for the study. It is focused on patterned behavior that was elaborated by five steps, including individual intrapersonal factors, interpersonal factors and primary groups, institutional factors, community factors, and public policy (K. R. McLeroy et al., 1988). These five steps of the ecological model indicate the range of strategies for interventions to promote public well-being within a community and within a particular social environment (D. Stokols, 1996), which in this study was the bystanders’ perspectives on their provision of informal, hospital-based care to bedridden patients with cancer in Sri
Lanka. This ecological model was successfully used in this study as a conceptual framework that guided the data analysis process of the study. Accordingly, the study findings were generated and summarized revisiting each steps of the socio-ecological model as follows.

**Intrapersonal Factors**

The intrapersonal factor, the first level of the ecological model, is the most specific factor that influences the role of the bystander. For this study, the individual characteristics of bystanders that influenced patients’ care include personal attributes such as family bonds, cultural and religious influences, knowledge and attitudes about caring, and skills/training related to the caring process. These intrapersonal attributes of bystanders influenced the well-being of cancer patients as well as bystanders themselves, either directly or in conjunction with a variety of social and contextual circumstances of the various types of bystanders such as being a close relative or family friends (unpaid), or being a paid and military personnel in this study.

**Interpersonal Factors**

The findings from this study indicated that individual preferences for informal caring are influenced by close ties with family, partners, or friends, and social interactions in a social network that an individual can rely on to offer emotional, information, or physical or material support in relation to informal caregiving. Bystanders also studied how to deliver informal care by observing others’ experiences (colleague
bystanders) within a social network in the ward. In addition, individual characteristics can affect the social networks to which bystanders have access in the clinical setting of this study. An individual’s social networks are also largely developed within the context of the hospital community and social environments that bring people into contact with other bystanders and health care workers specially nurses. Most unpaid bystanders were afraid to talk with nurses as they were assumed that the bystanders would be blamed for any error that occurred. Overall, it was noted that interpersonal relationship between the bystanders and the nurses or other supportive health care workers was not satisfactory.

**Institutional Factors**

A third level of the social-ecological model is the organizational or institutional level. Institutional/organizational characteristics directly influence the workers and clients. This level is also used to support behavioral changes in the people who are part of the organization. Bystanders in this study were highly influenced by the organization. Given that bystanders in this setting were not directly related to the workforce of the cancer hospital in Sri Lanka, they mainly needed to respect the hospital’s general common rules and regulations. Although there were many bystanders in the cancer hospital, there was no legal framework to protect them or their patients. Management styles of the hospital director, lack of support for the bystanders from the hospital staff, poor relationships between bystanders and health care workers, lack of basic facilities including sanitary facilities and communication problems were also identified as organizational or institutional level factors that directly influenced the bystander role.
Community Factors

Community is described as the mediating structures or face-to-face primary groups to which an individual belongs. In this study it was found that support for informal caregiving was received from the primary groups in the bystanders’ communities to which they belonged, including mainly their own families, close friends or neighborhoods, some government organizations such as the Sri Lanka Army, temples, and some private health care agencies that supply the paid bystanders. This study also identified that such resources directly influenced bystanders’ views and preferences for care provided at the bedside for bedridden patients with cancer. It was further identified that, in the community, resources were taking place in a variety of forms, including agency people who possess knowledge and skills, and from settings that could provide venues, such as temples that facilitate temporary residencies for people from out of town, for interaction amongst the people housed there. Therefore, it was indicated that the interrelatedness of the practice of caregiving within single wards of the hospital, as well as the links between multiple settings and caregiver practice within the broader community, played significant roles in the importance of community for the bystander. This helped to understand the broader role of the bystander in this study.

Public Policy

The use of public policies, procedures, and laws contributes to protect the health of the community as well as the country. This found that the laws and policies need to be standardized in order to ensure proper practice in health care, especially related to
caregiving of the bystanders. Bystander service is not an accepted service everywhere in Sri Lanka. The findings of this study indicated that the use of bystanders was initiated by the patients or the patients’ family members with or without request from the hospital staff. However, even though nurses did not initiate the inclusion of bystanders as part of the team, due to the shortage of nurses and the supportive staff, nurses expected to have a bystander at the bed side, especially for bed ridden patients who needed individualized care. Therefore, it is imperative that public policies be developed that address the acceptance and legalization of the bystander/informal caregiver service in Sri Lanka. Rules and regulations can be made to legalize the agencies who can supply the trained bystanders with a nominal fee. Additionally, the government can further explore options regarding the development of the informal caregiver category within their free health care service. These policy initiatives can help not only the patients who need assistance but also the families and the communities by providing trained, quality and affordable bystander service for quality care, thereby lessening the family burden.

Overall, this socio-ecological model was pivotal in identifying the different levels of responsibilities of bystanders in this study. The goal of the study was not only to explore each of the layers in this model but also to guide the data analysis process. The use of this model generated the fruitful findings related to the bystanders’ perspectives on their provision of informal, hospital-based care to bedridden patients with cancer in Sri Lanka.
Discussion of Study Findings

The study findings related to bystanders’ perspectives on their provision of informal, hospital-based care to bedridden patients with cancer in Sri Lanka will be discussed with the relevant literature in this section. How these findings can contribute to the literature on informal caregiving will also be presented.

Research Question One – Bystanders’ Perspectives

Many countries have bystanders; their presence has been documented in European countries, such as Italy, Greece, and Cyprus (Ambrosi et al., 2017; Papastavrou et al., 2009; Sapountzi-Krepia et al., 2008), and Asian countries, such as China, Iran, and India (Amiresmaili & Emrani, 2018; Chawak et al., 2019; Hui et al., 2013). In Sri Lanka, there are studies of informal caregivers of patients with dementia (Abeywickrema et al., 2015) and patients with stroke (Muthucumarana et al., 2018). However, there are no studies of informal care provided by bystanders in hospitals or for patients hospitalized with cancer in Sri Lanka. This is the first qualitative descriptive study that provides the bystanders’ perspectives on their provision of informal, hospital-based care to bedridden patients with cancer in Sri Lanka.

Two main perspectives of paid and unpaid bystanders and a unique subset of the “paid bystander” perspective held by the bystander participants were identified. The first perspective is based on the traditional family-based model of bystanders in Sri Lanka. Sri Lanka has a long tradition of caring for the sick not only in the community but also in institutions such as hospitals, built by ancient kings as early as the fifth and sixth
centuries under Buddhist influence (Hirschfeld, 2003). Though the caring concepts and the traditional family support system in Sri Lanka still exists, migration patterns, increasingly common dual-earning households, and a change from an extended family to a nuclear family structure all are contributing to a reduction in the availability of traditional volunteer caregivers (De Silva, 1994; Gaminiratne, 2004).

Research from India confirmed this situation. Frequently, a patient is admitted to the hospital, particularly in situations where the person is critically ill, and the extended family and/or close friends act as bystanders (Chawak et al., 2019). Unpaid family caregivers were all deeply committed to delivering care to their parents or loved ones who are elderly or sick and expressed a sense of pride in the role they played as a caregiver (Watt et al., 2014). The literature also highlights these unpaid caregivers as informal caregivers, to distinguish between professional caregivers, such as nurses and other healthcare workers (Scherbring, 2002).

The second perspective is based on a more recent model of commercial (paid) employment. According to Gaminiratne (2004), due to the implementation of family planning policies, family size has decreased, and family members find it hard to be available for hospitalized patients. This has led to having a paid bystander service, which is not yet formally established. Hui et al. (2013) pointed out that, rather than being performed by a family member, the role of the bystander in hospitals in China has become an occupation for some people who seek employment in the field of caring. This was the same situation in Sri Lanka, where paid bystanders engage with the job to earn money. According to Hui et al. (2013), private agencies have sometimes formed informal
small-scale agencies within hospitals or close to hospitals in China. Most of the paid bystanders in Sri Lanka also belonged to unofficial agencies established around the hospital. However, some independent bystanders did not belong to any agency.

An unreported bystander model emerged from this study. Findings from this study demonstrated a unique category of the bystander: a member of the Sri Lanka Army, acting as a bystander for another member of Sri Lanka Army, assigned to perform this duty by his or her superiors. This type of participant could be classified as an unpaid bystander; however, in the case reported in this study, the individual continued to receive his monthly salary from the Army while serving as a bystander for his colleague. Although he received a salary, which is important support, compared to unpaid bystanders who may lose employment while providing informal care, the “the unique model” bystander did not have prior training in informal care.

With this background of unpaid, paid and the unique subset of the “paid bystander” model bystanders, this study was initially interested in documenting informal care tasks. It was surprising to find that some bystanders perform many caregiver tasks without prior training: giving bed baths, turning the patent, giving bedpans, changing diapers and cleaning the perineal area, changing clothes, emptying the colostomy and urine bags, measuring urine, applying temporary dressings for bedsores, feeding via tubes, offering meals and drinks, transferring the patient to a wheelchair or trolley, and giving oral medication at the bedside. Many studies in other countries also described some of these bystander/informal caregiver tasks, such as in the United States (Miller et al., 2016; Waldrop, 2006), Greece (Stavrianou et al., 2018), Nigeria (Akpan-Idiok &
Anarado, 2014), Iran (Amiresmaili & Emrani, 2018; Hassankhani et al., 2019), and China (Hui et al., 2013). However, this study documented a wide range of tasks from morning to night across the 24-hour cycle. There were many special procedures, such as colostomy care, tracheostomy care, feeding via tubes, and even applying temporary dressings to patients’ bedsores, that were performed by the bystanders in this study and that do not receive attention in the literature.

In the existing literature, studies from China and India discussed paid bystanders and bystander agencies (Chawak et al., 2019; Hui et al., 2013), which is similar to this study. Iranian and European studies focused on bystanders who were relatives, described in this study as unpaid bystanders (Ambrosi et al., 2017; Amiresmaili & Emrani, 2018; Hassankhani et al., 2019; Papastavrou et al., 2009; Sapountzi-Krepia et al., 2008). This study focused on both types of bystanders. In addition, this study documented different groups of paid bystanders: bystander agency employees, independently paid bystanders, and the unique case of the military personnel who received a regular military salary while providing bystander care.

**Research Question Two – Bystanders’ Interactions with Nurses**

The existing literature highlights that it is not only patients admitted to the hospital who need assistance, but also health care workers. Particularly, nurses expect assistance from bystanders for bedside care (Hui et al., 2013; Sapountzi-Krepia et al., 2008). Bystanders in this study described the same situation, in which bystanders were
expected to do basic caregiving for patients as a way to assist nurses and other hospital staff.

However, there was no adequate information in the literature describing nurses’ interactions with bystanders. This study found that bystanders overwhelmingly described “working alone” and avoiding interactions with nurses. As nurses were perceived to be busy, difficult to talk with, and likely to blame the bystanders, bystanders described working alone as much as possible. Hence, both paid and unpaid bystanders reported managing all caring activities by themselves. A similar situation was also highlighted by Amiresmaili and Emrani (2018) in Iran. According to the authors, due to the shortage of nurses and their huge workload, nurses may not always fulfill bystanders’ expectations, which creates a problematic situation for the relationship between nurses and informal caregivers/bystanders and pushes bystanders to work alone.

Though many bystanders described working alone as much as possible, the findings highlighted that there were instances when bystanders needed to seek help from nurses, especially if the patient complained of any discomfort. This was highlighted by Hui et al. (2013) who examined the roles of caregivers in hospital bedside nursing care in China. Sometimes when caregivers requested help, nurses would help to fulfill the patients’ required tasks. It was evidence for the advocacy role of the bystander. Although it was difficult to find literature in this regard, Asif et al. (2019) identified that these bystanders would advocate for the patient, coordinate and manage care for the patient across settings, and organize communications between nurses and the health care
workers. According to Sadigh et al. (2016), once the true contribution of informal caregivers is known, a new model for patient care and advocacy can be established.

This study, focused on Sri Lanka, also identified bystanders as advocates for the patient and, in some instances, for the bystander. This is especially true for paid bystanders, as they are friendly with nurses. A good example was how nurses guided one paid bystander to become independent rather than working for an agency in order to earn more money. This was further evidence that the advocacy role of nurses can extend toward bystanders. According to the American Nurses Association (2017), the role of advocacy is expected from nurses and nursing in the care of individuals, families, communities, and populations.

Study findings further highlighted that this process of advocacy was not always smooth, as bystanders described nurses as busy and not always friendly, and that there were few nurses in the ward. Hengelaar et al. (2018) pointed out that nurses do not always work in partnership, given their limited meetings with informal caregivers. When reviewing the communication between professional and informal caregivers, it was only described in terms of difficulties: communications are insufficient and irregular and there are no best practices in many countries, such as Canada, Europe, United States, Australia, New Zealand, Israel, and South Africa (Hengelaar et al., 2018). Study findings from this research in Sri Lanka complements the existing findings in the literature. Although bystanders sometimes have been ignored by nurses or may experience conflicts with nurses, nurses and bystanders clearly need each other, especially to fulfill the care gap
due to the severe shortage of nurses, particularly in developing counties (Amiresmaili & Emrani, 2018; Hui et al., 2013).

Though nurses are busy with their workload, bystanders described some occasions when they received education from nurses. Findings from this study highlighted that nurses’ interactions with bystanders sometimes lead to nurses offering informal education related to caregiving. Hui et al. (2013) pointed out that bystanders could be trained and supervised properly by nurses, and cooperation between bystanders and nurses can improve patient care.

Overall, it can be concluded from this study that bystanders’ interactions with nurses occurred in the hospital setting while bystanders were providing bedside care. This was also evident in other developing countries (Amiresmaili & Emrani, 2018). Sometimes when caregivers requested help, nurses would help to fulfill the required tasks. This serves as evidence for the advocacy role of the bystander that was revealed by Asif et al. (2019). Bystanders highlighted that they were reluctant to interact with nurses because the nurses were busy, difficult to talk with, and ready to blame the bystanders, which was similar to the situation in many other countries (Amiresmaili & Emrani, 2018; Hengelaar et al., 2018; Hui et al., 2013). Bystanders’ interactions with nurses happened only for the fulfillment of essential caregiving tasks or to respond to patients’ needs, especially to manage pain. Hence, overall, the existing literature and findings from this study highlighted that interactions and communication between nurses and bystanders were identified as insufficient, irregular, and characterized by conflict or coordination,
and that no best practices exist to build effective interactions between nurses and informal caregivers to enhance informal caregiver practice within the hospital.

**Research Question Three – Bystanders’ Recommendations**

Two types of impacts on bystanders were identified in this study: health and socioeconomic. Both paid and unpaid bystanders faced health and economic constraints that needed to be addressed. Both types of bystanders presented their recommendations based on their experience in the current situation in developing countries, where it is difficult to deliver comprehensive nursing care by nurses themselves without having bystanders as informal caregivers (Hui et al., 2013; Muliira et al., 2019).

**Recommendations for the Acceptance of Bystander and the Bystander Service**

This study demonstrated that bystanders currently play an essential role in patient bedside care, especially for hospitalized patients with cancer as nursing depends on task-oriented nursing by nurses, themselves in varying degrees, which was also highlighted by De Silva and Rolls (2010). This finding further confirmed that the existence of unpaid and paid bystanders/caregivers requires the attention of hospital administrators and health authorities, which was also highlighted by Hui et al. (2013). According to the authors, the bystander’s role needs to be defined and closely monitored, a recommendation also supported by the findings from this study. However, if nurses could fulfill all the caring tasks for patients, the bystander service would not be required. Unfortunately, due to a
severe nursing shortage in Sri Lanka (De Silva & Rolls, 2010), this will be a challenging and long-term effort. Hui et al. (2013) pointed out that the allocation of all patient care to nursing staff will eventually improve? the quality of nursing care, but in the more immediate future, ample, if not fully adequate, nurse staffing will be an important factor in providing quality care and achieving better patient outcomes.

On the other hand, according to Hui et al. (2013), in Sri Lanka and China, inadequate nurse staffing often leads to the involuntary involvement of family members and privately hired caregivers in caring for hospitalized patients. Therefore, taking into consideration the current situation and the nature of Asian cultures, which emphasize family responsibility, bedside care can be continued with an acceptance of the informal caregiver/bystander category under the existing health system -- if these informal caregivers/bystanders are carefully observed and supervised by nurses. Nurses and policymakers should consider every possible way of meeting the needs of patients at the institutional and national levels. Further, the government/ministry of health can consider developing existing but limited attendant service or health care support staff service (Ministry of Health Nutrition and Indigenous Medicine, 2017) as an alternative, but this would not be cost-effective. As the structural pillars of hospital functions, informal caregivers should be given full recognition and support for their invaluable contribution to patient care (Sadigh et al., 2016).
**Recommendations to Uplift the Health of Bystanders Themselves.**

Both paid and unpaid bystanders revealed that they have limited facilities in the ward to perform their roles. They have limited places to stay and sleep, no adequate sanitary facilities, and no quality food, which leads to health hazards for the bystanders; ultimately, it influences not only the bystanders themselves but also the quality of informal caregiving.

All bystanders stated that there was not an adequate or designated place to stay with patients at the bedside. In Iran, informal caregivers also reported not having enough space (Amiresmaili & Emrani, 2018). In addition, Hassankhani et al. (2019) pointed out that adequate space needs to be considered for informal caregivers to take rest or to stay overnight with the patient. Bystanders in this study reported that when they sit on the chair overnight without proper sleep, it results not only in swollen legs but also headaches and the exacerbation of existing chronic conditions, which adversely influences the continuation of caregiving. Hence, study findings identified that bystanders’ highly recommend to the hospital director and the health ministry that consideration of the basic need for a suitable place and basic facilities to take rest or to stay overnight with the patient be addressed. This study is unique in obtaining and reporting recommendations directly from paid and unpaid bystanders themselves.

Bystanders also need to share common toilets and bathrooms with patients, which are often not adequately clean, and which can facilitate the transfer of diseases. There are no separate toilets or bathrooms for bystanders or even for visitors within the ward. Hence, all bystanders were concerned about their health and the risk of infections,
coming into contact with urine/feces, and coming into contact with drugs/radiation that was in the excretions. The same situation was emphasized by Amiresmaili and Emrani (2018) in Iran. This study of bystanders in Sri Lanka found that bystanders themselves recommended that hospital authorities and the government implement basic sanitary needs, such as separate toilets and bathrooms, to address the basic human and health care needs of bystanders and to protect patients.

Although bystanders are officially not allowed to get food from the hospital, even if there was leftover food after patients were served, ward staff sometimes gave it to the bystanders. However, there was a discrepancy in such food distribution and in getting nutritious food. Paid bystanders got priority because they have close relationships with hospital staff. Amiresmaili and Emrani (2018) also highlighted the lack of facilities for food for bystanders in Iran.

**Recommendations for Economic and Social Impacts on Different Types of Bystanders.**

Both unpaid and paid bystanders have faced economic issues. This can vary between unpaid and paid bystanders. Overcoming these economic problems to encourage bystanders to look after bedridden patients with cancer should be addressed.

Unpaid bystanders, who are a close family member or friends of patients, can lose employment, neglect their childcare needs, have trouble purchasing food and supplies, neglect taking their medication, have to pay lodging and travel fees -- all of which were identified as economic and social impacts. Cancer often leads to financial difficulties for
families. In Iran, as in many other Asian countries, men are often solely responsible for earning the family income (Hassankhani et al., 2019). A cancer diagnosis has an impact on families’ financial situations, particularly when the person receiving a diagnosis or the person who becomes a bystander for the patient is the primary income earner. According to Sadigh et al. (2016), some unpaid bystanders had to put jobs, businesses, and schooling completely on hold. Further, the authors highlighted that the majority believed that their families were also affected by a lack of financial support or physical presence. Hence, it would be prudent for the government policymakers to propose a satisfactory solution to overcome these economic issues.

Paid bystanders, who work for money and engage in employment, also faced such economic issues. Income discrepancy between independent and agency bystanders, the uncertainty of employment, lack of adequate duty shifts due to the monopoly of colleague bystanders and some health care workers, and difficulty in continuing workdays due to the lack of basic facilities were identified as the economic issues related to paid bystanders. Impacting the situation further, factors such as poor living conditions in the ward, long-term separation from family, an unstable job, and low income contributed to the high turnover of caregivers (Hui et al., 2013). Hence, it is recommended to the government, ministry of health, and hospital director to initiate policies to accept and formalize the paid bystander service to address such issues.
Recommendation to Have Bystander Education.

Both paid and unpaid bystanders recommended having at least basic education and training regarding informal care, as almost all bystanders have no formal training. Although some paid bystanders have many years of experience in caring, they also have no proper training or credentialing in informal care. Most unpaid bystanders come to look after their loved ones for the first time in their lives and have no experience. Therefore, at least basic education and training in informal caregiving were recommended by both paid and unpaid bystanders. A qualitative study of Iranian family caregivers also highlighted that caregivers need formal and comprehensive training about caregiving (Hassankhani et al., 2019). The study of Hui et al. (2013) in China reported that nurses depend on caregivers for bedside nursing care and, therefore, they need to be closely monitored by nurses. Muliira et al. (2019) elaborated on the need for oncology nurses in a sub-Saharan country to care for advanced cancer patients and to support and educate caregivers, especially in low-income settings with a high prevalence of cancer. Accordingly, it is recommended to have at least basic informal caregiving education and training for bystanders in Sri Lanka.

Findings from this study highlighted many recommendations that are similar to many other studies, especially related to Asian culture. However, many of these recommendations are not only important to the Sri Lankan context but also valid for many countries where the service of bystanders is needed. Hence, the respective policymakers should consider taking the necessary actions to implement these recommendations.
Implications

The important findings identified by this study need to be implemented appropriately. This section will include implications of the research findings for clinical practice, research, and policy implications related to informal caregiving.

Clinical Implications

Findings from this study conducted in Sri Lanka emphasized that all bedridden patients who cannot perform self-care activities by themselves need assistance. Further, due to the severe nursing shortage and a large number of patients, nurses are not able to provide individualized care. Hence, the findings from this study support the recommendation that a bystander or informal caregiver be provided for such patients. Even though having bystanders for patients has been practiced for many years, the role is still not properly recognized by the health authorities. It currently is not a compulsory or official practice. However, health care workers, especially nurses, expect to have a bystander for patients who need assistance. Findings from this study confirm the necessity of bystanders to the clinical setting to ensure quality care for hospitalized bedridden patients. However, the involvement of untrained caregivers in-hospital patients’ care may be a potential risk to patient safety (Hui et al., 2013), which needs to be closely monitored. Further, findings from this study remind us that the existence of bystanders requires the attention and intervention of hospital administrators and health authorities.
In addition, proper training is needed for these bystanders. According to Hui et al. (2013), nurses are required to help, supervise, and educate the relatives or caregivers of patients regarding proper bedside nursing care in China, which is also recommended in the Sri Lankan setting. Bystanders must be adequately prepared for their responsibilities to control their burden (Scherbring (2002)).

Hui et al. (2013) recommends that slowly swapping family-paid caregivers/bystanders with hospital nursing personnel and encouraging hospitals to take responsibility for all required nursing care will enhance hospital nursing care quality and achieve the goal of patient, societal, and governmental satisfaction. Hence, developing the nursing workforce is vital for quality patient care.

**Research Implications**

Replication of this study with a larger and more diverse bystander population is indicated. This may include patients and bystanders from multiple health care settings. Specifically, as the need for palliative care becomes more recognized, more research on this topic is needed as it relates to cancer (Scherbring, 2002). However, as most countries have faced a nursing shortage, and bystanders/informal caregivers already exist in many countries, it is highly recommended that more research be conducted to explore and determine how bystanders or informal care services can be utilized effectively to enhance the quality of care in hospital settings.

What is missing in the literature are studies comparing paid and unpaid bystanders for hospitalized patients. Many studies explored informal family caregivers, but limited
literature relates to paid informal caregivers (Hui et al., 2013). Future qualitative studies that incorporate nurses’ perspectives on what allowed them to seek and receive informal care is also warranted.

The main limitation of this study was that the findings come from a relatively small number of bystanders in Sri Lanka. Further, as this is a qualitative study, the findings may not be generalizable. A large-scale investigation of bystanders in various parts of Sri Lanka needs to be completed to uncover the complete picture of the role of the bystander in Sri Lanka. Further, research examining the perception of nurses and bystanders about the development of informal care services in specialized areas, such as medical and surgical units, and emergency units in Sri Lanka, could add important and useful information to the Sri Lankan nursing literature.

Future research could explore nurses’ perspectives with the aim of ascertaining how best to help nurses integrate bystanders into the “team of care”. Due to the shortage of nurses, they like to have bystanders with the patients to help patients’ selfcare, which improves nurse staffing. Additionally, to explore how nurses engage with bystanders, it would be helpful to study the interactions between nurses and bystanders in a hospital setting in order to more fully understand what an engaged nurse/bystander relationship should encompass.

Overall, the bystander service needs to be evaluated through the lens of bystanders, nurses and policymakers to explore the advantages and disadvantages of having the bystanders in the health care system. A proposed research agenda is presented in Table 5.5.
Table 5.5. Research Agenda

<table>
<thead>
<tr>
<th>Target Population</th>
<th>Research topics</th>
<th>Research methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bystanders</td>
<td>1. The need of ‘Bystander Service’ or Informal care service for Sri Lankan Health care setting: Bystanders perspectives.</td>
<td>Qualitative Quantitative</td>
</tr>
<tr>
<td></td>
<td>2. How bystanders or informal care services can be utilized effectively to enhance the quality of care in hospital settings: Bystanders perspectives.</td>
<td>Qualitative Quantitative</td>
</tr>
<tr>
<td></td>
<td>3. Paid bystanders’ perspectives on caregiving (Different clinical settings can be used)</td>
<td>Qualitative descriptive</td>
</tr>
<tr>
<td></td>
<td>4. Unpaid bystanders’ perspectives on caregiving (Different clinical settings can be used)</td>
<td>Qualitative descriptive</td>
</tr>
<tr>
<td></td>
<td>5. Overall bystander role in Sri Lanka (A large-scale investigation of bystanders in various parts of Sri Lanka needs to be completed to uncover the whole picture of the role of the bystander in Sri Lanka)</td>
<td>Quantitative Survey</td>
</tr>
<tr>
<td></td>
<td>6. The perception of bystanders about the development of informal care services in specialized clinical areas, such as medical and surgical units, and emergency departments in Sri Lanka.</td>
<td>Qualitative</td>
</tr>
<tr>
<td></td>
<td>7. Bystanders’ expectations for enhance existing informal caregiving.</td>
<td>Qualitative</td>
</tr>
<tr>
<td>Nurses</td>
<td>1. Nurses perception about the need of bystander.</td>
<td>Qualitative</td>
</tr>
<tr>
<td></td>
<td>2. The perception of nurses about the development of informal care services in specialized clinical areas, such as intensive care units, medical and surgical units, and emergency departments in Sri Lanka.</td>
<td>Qualitative</td>
</tr>
<tr>
<td></td>
<td>3. Nurses’ expectations from the bystanders in caring process.</td>
<td>Qualitative Quantitative</td>
</tr>
<tr>
<td></td>
<td>4. Nurses’ concerns about existing nursing workforce.</td>
<td>Qualitative</td>
</tr>
<tr>
<td></td>
<td>5. How best to help nurses integrate bystanders into the “team of care”.</td>
<td>Quantitative</td>
</tr>
<tr>
<td>Policy Makers</td>
<td>1. The role of the Ministry of Health in establishing acceptable bystander service.</td>
<td>Qualitative Quantitative</td>
</tr>
<tr>
<td></td>
<td>2. Explore the need of bystanders for existing health care system.</td>
<td>Qualitative</td>
</tr>
<tr>
<td></td>
<td>3. What are the basic facilities that need for bystander from the wards and the hospital level?</td>
<td>Quantitative</td>
</tr>
</tbody>
</table>
Policy Implications

Nurses and policymakers should consider all possible ways of meeting the basic care needs of patients at the institutional and national levels. These needs should be met by hospital nursing personnel as often as possible, with the ultimate goal of quality care and a harmonious relationship between nurses and patients (Hui et al. 2013). Unfortunately, due to the lack of a sufficient number of nurses, this is a question not only in the Sri Lankan context but also in many other countries. Hence, it is highly recommended that policies be initiated that establish a new link between nurses and patients, including trained and accepted bystander service/informal caregiving service, to fill this gap. Policymakers need to consider that, in the future, the current bystander service will be gradually replaced by the nursing workforce for the betterment of quality care.

Further, the study findings provide evidence that the Sri Lankan public hospital system requires or expects a bystander for every hospitalized patient who needs assistance, but it does not provide the facilities or support needed to facilitate bystander care. One implication is the need to appoint a committee to look into bystanders’ needs. The Ministry of Health and the Health Minister should prepare a cabinet paper to inform the public and inform future policy. The committee should include medical officers, nursing leaders, paid bystanders, independent bystanders, unpaid bystanders, bystander agency owners, hospital directors, researchers, and experts in cancer care, palliative care, and end-of-life care.
These initiatives may be of interest to policymakers and health authorities to help them design plans to develop the health care system, aiming to improve the degree of satisfaction of and improved outcomes for consumers of the Sri Lankan health system. Hence, funding needs to be made available to make reforms possible. These reforms can be prioritized in terms of immediate and long-term actions (Table 5.6).

Table 5.6 The List of Policy Recommendations

<table>
<thead>
<tr>
<th>Policy Recommendations – Immediate Actions</th>
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<tbody>
<tr>
<td>• Nurses and policymakers should consider all possible ways of meeting the basic care needs of patients at the institutional and national levels. Hence, immediate policy initiatives should focus to,</td>
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<tr>
<td>• accept and regularize the existing bystander service in hospital level.</td>
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<tr>
<td>• give suitable basic training for existing and new bystanders. Nurses may facilitate it.</td>
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<tr>
<td>• provide the facilities or support needed to facilitate bystander care.</td>
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<tr>
<td>• increase basic facilities for bystanders within the hospital premises such as sanitary facilities.</td>
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<td>• establish agencies that supply trained caregivers or government should take actions to increase existing attendants/supportive staff service.</td>
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<table>
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<tr>
<th>Policy Recommendations – Long Term Actions</th>
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</thead>
<tbody>
<tr>
<td>• Appoint a committee to investigate bystanders’ needs in long term. The committee should include medical officers, nursing leaders, paid bystanders, independent bystanders, unpaid bystanders, bystander agency owners, hospital directors, researchers, and experts in cancer care, palliative care, and end-of-life care.</td>
</tr>
<tr>
<td>• The Ministry of Health and the Health Minister should prepare a cabinet paper to inform the public and inform future policies related to these bystander service.</td>
</tr>
<tr>
<td>• Long term plan to increase nursing workforce for individualized care.</td>
</tr>
<tr>
<td>• Policymakers need to consider that, in the future, the bystander service will be gradually replaced by the nursing workforce for the betterment of quality care.</td>
</tr>
</tbody>
</table>
Conclusion

This qualitative descriptive study of bystanders’ perspectives on their provision of informal, hospital-based care to bedridden patients with cancer in Sri Lanka demonstrates the essential role bystanders play in patient care and advocacy. By listening to the bystanders, themselves, this study presents findings that can help to address the challenges that bystanders experience. By examining the perspectives of paid and unpaid bystanders, a more complete picture of the circumstances of bystander informal care can be better understood. Bystanders need to be actively involved in future efforts to improve care for patients with cancer in Sri Lanka. As potential members of palliative care teams, bystanders can advocate for patients with cancer. National governments and hospital directors can utilize the findings from this study to establish a formal bystander service, while also attending to the shortage of nurses in Sri Lanka and developing new roles in health care, such as nurses’ aides. Future research can expand the focus to include nurses’ perceptions of bystanders and what training is sufficient for bystanders. Studying the role of bystanders with non-cancer patients across the country and around the world will contribute to the quality of care for all patients.

Further, the recommendations indicate that government-level policies need to be prepared to ensure the acceptance of the bystander service. The Ministry of Health needs to implement those policies through hospital directors for the betterment of the bystander service. It will help to combat the dearth of patient care due to the shortage of nurses, resulting in quality patient care.
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Dear Prospective Participant,
Researchers at the University of New Mexico are inviting you to take part in a research interview about the types of caring that informal care giver in the hospital do for patients with cancer. The title of this study is “Informal care giver’ perspectives on the provision of informal, hospital-based care to in-patients with cancer in Sri Lanka.” We know that informal care giver does all kinds of caring, but no researchers have talked to informal care giver themselves and asked about their experiences or their perspectives. We also want to learn what is needed to help or support the bystander.

WHAT ARE THE KEY REASONS YOU MIGHT CHOOSE TO VOLUNTEER FOR THIS STUDY?
Although you may not get personal benefit from taking part in this research study, there are some reasons you might want to volunteer to do an interview. Your responses may help us understand more about what informal care giver actually do. Also, by answering the interview questions, you may help us identify ways for nurses, hospitals, and policy makers to support the informal care giver in doing their work.

WHAT ARE THE KEY REASONS YOU MIGHT NOT CHOOSE TO VOLUNTEER FOR THIS STUDY?
- This study is completely voluntary and will not offer money or any merchandise for your participation.
- Some individuals might feel uncomfortable emotions when talking about their experiences as a bystander. Each person who participates in the interview will be provided with the phone number of a hospital counseling department where they can access a counselor to speak with free of cost.
- The phone interview will be audio-recorded and transcribed. Some people might not feel comfortable having the interview audio-recorded and written down. The researchers will protect your interview data by using password protections and encryption so that others can’t access the information. The researchers will also delete any names or other identifying information mentioned in your interview, including your own name or the names of family members. Even though the study will take these actions to protect your interview information, there is always a small risk that the confidentiality of your information could be compromised.

You will not be paid for taking part in this study. The interview will take about 60 minutes to complete. We will do the interview over the phone or using Zoom.
There is a small risk of loss of confidentiality in this study. It is possible that research materials could be lost or stolen or hacked on the internet. We will take every measure to keep research materials stored on password-protected computers and kept on the secure UNM College of Nursing server. The audio files will be encrypted, and password protected.

Your answers to the interview questions will be kept confidential to the extent allowed by law. When we write about the study and its results you will not be identified. Your name and any family members’ names or other people’s names will not be identified. Any identifiable information that gets mentioned in the interview (such as your name, a patient’s name, a nurse’s name, a family member’s name, or the name of your hometown or any healthcare facility) will be removed from the information collected in this study.

We hope to interview approximately 20 informal care givers, so your participation is important to us. Of course, you have a choice about whether to participate. If you decide to participate, during the interview you are free to skip any questions or stop doing the interview at any time.

Please be aware, while we make every effort to safeguard your data once received on our UNM College of Nursing server, as with anything involving the Internet, we can never guarantee the confidentiality of the data.

If you have questions about the study, please feel free to ask; my contact information is given below. If you have questions regarding your legal rights as a research subject, you may call the UNM Human Research Protections Office at 1+(505) 272-1129.

Thank you in advance for your assistance with this important project. By giving your verbal agreement to Mr. De Silva (Co-Investigator), you will be agreeing to participate in the above described research study.

Sincerely,

Dorinda L. Welle, PhD
(Principal Investigator)
UNM College of Nursing,
University of New Mexico Health Sciences
PHONE: 1+505-272-4142
E-MAIL: dwelle@salud.unm.edu

B. Sunil S. De Silva, RN, B.Sc.N, MN
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UNM College of Nursing,
University of New Mexico Health Sciences,
PHONE: 0112881325(325)
E-MAIL: bdesilva@salud.unm.edu
Appendix B

IRB Approved Consent Form – Sinhala Version

Template v5/23/2019

IRB නිකරණය වේගත්වමින් සිරිත්වේදියක් අදාරපුර්වයේ මිනිසා පැහැදිලී ස්ථානයක් මෙහෙඳින් කොටසක්
Appendix C
Qualitative Interview Guide – English Version

Bystanders’ Perspectives on the Provision of Informal, Hospital-based Care to In-patients with Cancer in Sri Lanka

Qualitative Interview Guide

Research Question 1: Provision of Informal Care by the Bystander

Question 1A: Please tell me how you became a bystander.

Question 1B: Please tell me all of the various things you do to help take care of the patient. Let’s start with what things you do in the morning. (Then probe for activities done in the afternoon, and at night.)

Question 1C: When you are helping to care for the patient, what are the challenges or difficulties you experience? (Probe for challenges related to specific tasks.).

Question 1D: What is the most difficult thing about being a bystander?

Research Question 2: Bystanders’ Interactions with Nurses

Question 2A: Please tell me about times you have interacted with the nurses. When have you needed to get help from a nurse?

Question 2B: Can you tell me what happens when you ask for help from a nurse? How do the nurses respond to your requests?

Research Question 3: Bystanders’ Recommendations

Question 3A: What do you recommend for improving the situation for people who are bystanders?

Question 3B: What things could the hospital or the national government do to make bystander care easier to provide?
Appendix D
Qualitative Interview Guide – Sinhala Version

ඉංගරිIVO නම්වන්නා කවුරුම්කම් සම්ප්‍රදායක්, පරිශීල්ඨ සංකල්පයන් විසින් තරණියේ විශේෂීය නිර්මාණය යාමක් කරන අංගයක් මිලදා නිසාවන්දාව

ඉංගරිIVO නම්වන්නා කවුරුම්කම් සම්ප්‍රදායක්

ඉංගරිIVO නම්වන්නා කවුරුම්කම් සම්ප්‍රදායක් නිර්මාණය කිරීම

ඉංගරිIVO නම්වන්නා කවුරුම්කම් සම්ප්‍රදායක් නිර්මාණය කිරීම සම්ප්‍රදායක් නිර්මාණය කිරීමේ නිවසයක්.

ඉංගරිIVO නම්වන්නා කවුරුම්කම් සම්ප්‍රදායක් නිර්මාණය කිරීම සම්ප්‍රදායක් නිර්මාණය කිරීමේ නිවසයක්. (ඉංගරිIVO නම්වන්නා කවුරුම්කම් සම්ප්‍රදායක් නිර්මාණය කිරීමේ නිවසයක්)

ඉංගරිIVO නම්වන්නා කවුරුම්කම් සම්ප්‍රදායක් නිර්මාණය කිරීම සම්ප්‍රදායක් නිර්මාණය කිරීමේ නිවසයක්. (ඉංගරිIVO නම්වන්නා කවුරුම්කම් සම්ප්‍රදායක් නිර්මාණය කිරීමේ නිවසයක්)

ඉංගරිIVO නම්වන්නා කවුරුම්කම් සම්ප්‍රදායක් නිර්මාණය කිරීම සම්ප්‍රදායක් නිර්මාණය කිරීමේ නිවසයක්.

ඉංගරිIVO නම්වන්නා කවුරුම්කම් සම්ප්‍රදායක් නිර්මාණය කිරීම සම්ප්‍රදායක් නිර්මාණය කිරීමේ නිවසයක්. (ඉංගරිIVO නම්වන්නා කවුරුම්කම් සම්ප්‍රදායක් නිර්මාණය කිරීමේ නිවසයක්)

ඉංගරිIVO නම්වන්නා කවුරුම්කම් සම්ප්‍රදායක් නිර්මාණය කිරීම සම්ප්‍රදායක් නිර්මාණය කිරීමේ නිවසයක්.

Version 04.17.2020
Appendix E

IRB Approved Letter

May 10, 2020
Dorinda Welle
DWell@salud.unm.edu

Dear Dorinda Welle:

On 5/10/2020, the HRRC reviewed the following submission:

Type of Review: Modification / Update
Title of Study: Bystanders’ Perspectives on the Provision of Informal, Hospital-based Care to In-patients with Cancer in Sri Lanka
Investigator: Dorinda Welle
Study ID: 20-230
Submission ID: MOD00011714
IND, IDE, or HDE: None

Submission Summary: Modification #1 for Study 20-230 to add Consent and Supporting Documents.

Documents Approved/Acknowledged:
- Bystanders Verbal Consent Script SINHALA
- Bystanders Accuracy of Translation Letter
- Bystanders Qualitative Interview Guide SINHALA

Review Category: EXEMPTION: Categories (2)(ii) Tests, surveys, interviews, or observation (low risk)


Submission Approval Date: 5/10/2020
Approval End Date: None
Effective Date: 5/10/2020

The HRRC approved the study from 5/10/2020 to inclusive. If modifications were required to secure approval, the effective date will be later than the approval date. The “Effective Date” 5/10/2020 is the date the HRRC approved your modifications and, in all cases, represents the date study activities may begin.

Because it has been granted exemption, this research is not subject to continuing review.
Human Research Protections Program

Please use the consent documents that were approved by the HRRC. The approved consents are available for your retrieval in the "Documents" tab of the parent study.

If the study meets the definition of an NIH Clinical Trial, the study must be registered in the ClinicalTrials.gov database. Additionally, the approved consent document(s) must be uploaded to the ClinicalTrials.gov database.

As a reminder, it is the responsibility of the principal investigator or delegated study team member, to re-consent former and/or current participants as directed in the “Determinations/Waivers” section of this letter.

This determination applies only to the activities described in this submission and does not apply should you make any changes to these documents. If changes are being considered these must be submitted for review in a study modification to the HRRC for a determination prior to implementation. If there are questions about whether HRRC review is needed, contact the HRPO before implementing changes without approval. A change in the research may disqualify this research from the current review category. You may submit a modification by navigating to the active study and clicking the “Create Modification/CR” button.

If your submission indicates you will translate materials post-approval of English materials, you may not recruit or enroll participants in another language, until all translated materials are reviewed and approved.

In conducting this study, you are required to follow the Investigator Manual (HRP-103), which can be found by navigating to the IRB Library.

Sincerely,

Thomas F. Byrd, MD
HRRC Executive Chair

Abbreviated Investigator Responsibilities

NOTE: For a full unabbreviated version of the Investigator Manual, please visit the HRPO website at https://hsc.unm.edu/research/hrpo/.

What will happen after HRRC review?
Appendix F
Letter of Support – Apeksha Hospital, Sri Lanka

To: Dorinda Welle, PhD and B. Sunil S. De Silva, RN, BScN, MN(Res)

RE: Letter of Support for External Site

Dear Dr. Welle and Mr. De Silva:

The Apeksha Hospital supports the collaboration with the University of New Mexico College of Nursing for Mr. De Silva to conduct recruitment and data collection activities for the qualitative research study entitled “Bystanders’ perspectives on their provision of informal, hospital-based care to bedridden patients with cancer in Sri Lanka.”

We support the research aims of this study, which are to describe: 1) bystanders’ perspectives on providing informal care for bedridden patients with cancer in hospital settings in Sri Lanka, 2) bystanders’ perspectives on their interactions with nurses, and 3) the recommendations of bystanders to improve informal care for bedridden cancer patients in hospital settings in Sri Lanka.

As Director of Apeksha Hospital, I authorize Mr. De Silva’s on-site recruitment of bystanders, including his distribution of the study flyer to bystanders on the wards and placing the study poster in the wards. In addition, a private meeting room will be provided, where Mr. De Silva can conduct on-site interviews. We support Dr. Welle and Mr. De Silva’s involvement in this effort, and their investment of time on the project.

I also understand that this study will not collect Private Health Information from our hospital or from individual research participants. In addition, I understand that the names of any hospital staff will be removed from the data. Appropriate hospital staff will be informed of the study and instructed to respect the confidentiality of bystanders who consent to participate. Bystanders who decline research participation will receive the same respect and staff support that all bystanders receive at Apeksha Hospital.

Thank you for facilitating this important effort. We look forward to the collaboration with you.

Dr. Wasantha Dissanayake,
Director,
Apeksha Hospital,
Maharagama.