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DEVELOPMENT OF CARE MODEL FOR GOOD DEATH OF ELDERLY RESIDENTS IN LONG-TERM CARE FACILITIES

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ABSTRACT

As Taiwan is already an aging society, increasing attention should be paid to the physiological and psychological problems of the elderly. The elderly is more likely to show anxiety about the arrival of death than the young; however, the needs of institutional dying elderly residents are easily ignored. Therefore, institutional hospice care must be emphasized and developed. This study conducted qualitative in-depth interviews, on-site care methods, and literature review to discuss a successful model for facilities to promote hospice care. The author divided the institutional hospice care model into three dimensions: facility, family, and residents. This study used the concept of care for the whole person, the whole process, the whole family, the whole team, and the whole community, as well as the relationships among the factors, as the spiritual core to assist dying residents in achieving harmonious relationships during the process of facing death. This study may serve as reference for facilities to develop a hospice care model to improve institutional hospice care quality and further elevate the quality of life of dying residents and their family members.

Keywords: *Care Model, Good Death, Elderly Residents, Long-term Care Facilities*

1. INTRODUCTION

Long-term care for the elderly has long been an issue of common international concern (Ministry of the Interior, 2020). As of the end of December 2020, the proportion of elderly people over 65 in Taiwan reached 16.07% of the total population, and by 2026, the elderly population is expected to reach 20% of the total population, meaning that one-fifth of the population in Taiwan will be 65 years old. In the face of the rapid growth of the elderly population, the physical and psychological care of the elderly has attracted increased attention (Araújo de Freitas et al., 2020; Tu et al., 2017). In Taiwan, there were 670,000 disabled people nationwide (of which 61% were elderly) in 2011. It is estimated that the number of elderly people with disability will increase to 660,000 by 2023 (Ministry of Health and Welfare, 2020). Due to social changes, changes in family structure, aging, declining birthrates, and fewer traditional care functions being undertaken by families, the demand for long-term care is increasing. Family support factors for the elderly are affected by multiple factors, such as population, economy, politics, and culture. Long-term care is regarded as an item that must be provided for elderly welfare services, and institutional care has become a necessary type and method of care service (Huang, 2017). The elderly are more likely to show anxiety about the arrival of death than the young, and the needs of institutional dying elderly residents are easily ignored. As dying elderly residents are unable to express their needs, their family members have to make various decisions for them (Araújo de Freitas et al., 2020; Huang et al., 2015). Unlike patients with cancer or other diseases with high morbidity rates, dying elderly patients cannot anticipate the arrival of death, thus, the choice of their place of death is often made by family members who have decision-making power; decision-making will be affected by many factors, including decision makers (individuals or groups), decision maker's special environment (including natural, cultural, and behavioral interaction conditions), and decision maker's subjective goal. The decision makers themselves will also be affected by their group or role status, personality, educational level, beliefs, etc. (Smith et al., 2020; Chen et al., 2018).

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Faced with the vigorous development of long-term care facilities, as the direct care professionals who contact patients and their family members, how nurses can help patients and their family members who are choosing to die in a facility at an appropriate time and place, and understand their needs to enhance the quality of institutional hospice care, are issues that require great attention. This study chose a facility that has successfully promoted hospice care in Taiwan as the study site, and used in-depth interviews and on-site participation in care to understand the status of the facility's promotion of hospice care. In addition, this study conducted a literature review to develop the institutional hospice care model.

2. LITERATURE REVIEW

2.1 The Dilemma of Institutional Dying Residents Admitted to Emergency Care

With the advent of an era of population aging, an increasing number of people choose to have elderly patients suffering from serious chronic diseases reside in long-term care facilities. Thus, long-term care facilities have become the inevitable or suitable choice of residence for some elderly people in modern society. The places where the elderly die often become the facilities where they live; on the contrary, in the family home is no longer the only place where the elderly choose to die (Huang, 2017). Limited by the system, when dying elderly residents in a facility have health problems, the facility faces a dilemma regarding whether to "admit the dying resident to the hospital", which conflicts with the principle of hospice care and good death.

Past studies found that when residents in long-term care facilities are admitted to an emergency room, they often face various emergencies or invasive treatments that cause "both physical and psychological pain", and thus, they fail to die peacefully. In addition, this situation also causes emergency medical teams into the dilemma of choosing between "proactive rescue" and "palliative care". In the past decade, while the awareness of a "good death" has gradually risen in Taiwan, elderly people often encounter a situation where they do not have an appropriate scenario or opportunity to discuss "Do Not Resuscitate (DNR)"-related issues. If the concept of hospice and palliative care can penetrate the community, and the emergency departments of community hospitals can undertake the burden of incomplete hospice and palliative care, then the quality of life and dignity of the residents at the end of life can be reversed. For residents at the end of life in long-term care facilities, it is an important opportunity and bridge (Harrison, 2017). At present, most facilities are worried about medical disputes, thus, when residents are in danger of their life ending, they are first sent to the hospital for treatment. Long-term care facilities still have a lot of room for improvement in end-of-life care (Hiraoka et al., 2020). Past studies indicated that, how the staffs of the facilities handle the death of residents in the facilities, as well as the atmosphere in the facility, will affect the residents' attitude towards death. Similarly, more than 80% of institutional residents expect that health care providers will inform them when their familiar residents die (Kim, & Jeong, 2019). Thus, health care providers are important regarding the attitude towards the death of institutional residents.

2.2 Connotation of hospice care

Currently, the world attaches great importance to hospice palliative care. In the 4-level cancer prevention care in Taiwan, the fourth level is to prevent suffering, which is consistent with the concept of hospice palliative care. As it is not only the patients with cancer who suffer from the end-stage of illness, in recent years, the service target has been expanded to patients with other severe end-stage illness, such as patients with end-stage multiple organ failure, thus, such patients can also choose the service of hospice and palliative care (Collingridge et al, 2020). The concept of hospice palliative care is that if a disease cannot be cured, it has progressed to the terminal stage, and death is the expected situation, the goal is not to recover from the disease, but to take care of the patient and improve the quality of life of the patient and his/her family members. For patients with end-stage illness, the concept of complete care, which includes five complete care steps, has been proposed, including the care concepts of whole person, whole process, whole family, whole team, and whole community (Xiong et al., 2021). Whole person care refers to the complete care of the body, mind, spirit, and society of patients with end-stage illness. Most non-hospice wards attach importance to only physical care. Whole process care refers to the overall care for patient receiving hospice palliative care from the diagnosis of disease to the sad consultation with family members after the patient's death. Whole family care means that family members and patients are both the key objects of care. Family members may have to face many major choices during the

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care of a patient, and experience unspeakable sad reactions, thus, special care for family members will also allow patients to reach a perfect end. Whole team care refers to the combination of physicians, nursing personnel, psychological counselors, social workers, religious teachers, or volunteers that jointly take care of patients and their family members. Whole community care enables community residents to take part in the caregiver role, accept patients returning to the community, and empathize with the situations and psychological reactions of family members (Jennings et al., 2020).

The needs of terminally ill patients include: (1) to minimize physical pain. (2) to receive comfort care and maintain dignity and peace; (3) to make medical choices without regrets; (4) to feel relieved and have their family members rest assured; (5) to say thank you, apologize, express love, and say goodbye; (6) to feel satisfied and complete a meaningful life. Health care providers should possess the following necessary knowledge, skills, and attitudes: (1) survival prediction; (2) prognosis prediction; (3) trajectories of illness prediction; (4) assisting patients in setting their own treatment goals and priorities; (5) symptom recognition, assessment, and treatment; (6) comfort care; (7) psychological, social, and spiritual care; (8) communication and message transmission; (9) being able to make relevant ethical reflections; (10) ethical and legal considerations and choices for stopping inappropriate treatment; (11) care for family members before and after death; (12) ability to reflect (Chao, 2015).

Relationship is the core of spirituality. Nurses can use the model of Stoll (1979) as a guide to provide spiritual care plans to help patients create a harmonious relationship with heaven, people, things (nature), and themselves in the process of illness, to transcend the shackles of sickness, and rebuild personal value and hope. Using the family-centered concept, nursing personnel can assist in the communications between family members and patients. However, while the repair of interpersonal relationships is not under the control of nursing personnel, they can use humanized care to stimulate the motivation of patients to fight against disease (Chao, 2020). Personal companionship, empathy, and listening are indispensable in the humanized care process. Regarding the patients' religious beliefs, the nursing personnel can guide and intervene religious care as needed. Aromatherapy, music therapy, painting, and writing can also help patients calm down or express their inner emotions (Currow et al., 2020). However, spiritual care must be rooted in high-quality physical care, thus, the control of disease symptoms and the provision of comfort care are the cornerstones for the success of spiritual care (Huang et al., 2020).

3. METHODS

In order to develop the institutional hospice care model, the author selected one institution in Taiwan that has successfully promoted hospice care as the study site. This study used in-depth interviews and on-site participation in care to collect data. This study interviewed 9 persons (one person in charge of the institution, one consultant, one head nurse, two nurses, two clinical caregivers, and two family members who were the primary decision makers for elderly residents passing away in the institution), in order to understand the experience of proving hospice care for dying elderly persons in the long-term care facility, and further arrange the essential factors for the institution to successfully promote hospice care to develop the institutional hospice care model.

4. RESULTS

This study integrated the results of interviews, on-site participation in care, and literature review to develop the institutional hospice care model (Figure 1), which aims to provide residents with hospice palliative care. The institution, family members, environment, and spiritual belief are connected through trust, and the relationships of trust are strengthened with perceived feeling, assistance, companionship, and peace. Moreover, this study also developed hospice care evaluation guidelines. According to the aspects of hospice and end-of-life care, this study designed a care plan and care guidelines according to three stages, including the stage of admission or change of disease condition, stage of coma, and stage of death (Table 1). Moreover, this study also designed hospice care evaluation forms and guidelines in the aspects of institution, environment, family members, and belief to assist nursing personnel in implementing end-of-life care plan procedures and providing actual care measures.

5. DISCUSSION

This study developed an end-of-life care model according to the properties of the institution (aspects

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of institutional care and environment, aspects of family members' trust, and aspects of religious spirituality). The theoretical bases include: the theory of social trust between people and the system, as proposed by Simmel (1950); the spiritual interaction model of humankind, as proposed by Stoll (1979): humankind's spirituality, also known as the value proposition of life, which originates from four directions, the gods, others, self, and the environment in which people believe. The starting point of Simmel's trust theory is interaction. He believes that it is interaction that forms society and the complicated relationships between people. Interactions between individuals are the starting point for the formation of all social components. While the true historical origin of social life is still obscure, systematic generative analysis must start from the simplest and most direct relationships, and even today, such relationships remain the source of countless new forms of social formations, from personal trust to system trust (Simmel, 1950).

Stoll (1979) proposed the interrelatedness nature of a person's spirituality. Human spirituality is composed of vertical and horizontal aspects; the vertical aspect refers to the relationship between an individual, the Supreme (God), and the environment, while the horizontal aspect refers to the relationship between an individual and himself/herself and others. Based on the interpretation of this model, humankind's spirituality (the value proposition of life) originates from four directions, the gods, others, self, and the environment in which people believe. In the process of growing up, most people build a sense of value for their own lives through mutual love, mutual trust, mutual acceptance, and forgiveness of others. However, as the age increases and the mind matures, through self-reflection or the insight of religious beliefs, some people can realize the value of self-existence beyond the interpersonal level. In addition, people may express their awe and respect for life through gratitude to the environment or nature. In short, the meaning and value of an individual's existence is constructed on a meaningful relationship to the individual, and the level of this relationship is not limited to complicated interpersonal interactions. People can re-examine their relationships with themselves, others, and the environment through the establishment of religious beliefs to further find their own position in their ever-changing life situations, and calmly face the good, evil, misfortune, and blessings of life (Swanson et al., 2019).

The development of institutional end-of-life care is an important topic in elderly care, and its goal is to improve the quality of life of the dying elderly and their family members (Xiong et al., 2021). The belief of the person in charge of the institution is an important element in the successful promotion of hospice care. When the person in charge leads the institutional health care providers to promote end-of-life care, the care providers will not be afraid to take care of the dying residents, and will accept the challenges with confidence. The establishment of a sense of trust between teams is important; when family members trust the care provided by nurses, clinical caregivers, and physicians, they will also trust the entire institution.Provided the residents who choose to die at the institution or their family members have no special objections, institutional end-of -life care can be continuously implemented. Moreover, the provision of the hospice environment is also a key point. It is recommended that institutions can provide a comfortable hospice environment for dying elderly residents, allow them to listen to familiar sounds in an environment familiar to them, and agree to let their family members accompany them 24 hours a day. When a resident dies in an institution, the institution will provide a solemn and respectful environment, and professionals will assist in the care of the body. The institution can also help issue a certificate of diagnosis and death through a special doctor, and can even assist in arranging for the transportation of the body in a suitable vehicle.

For family members, the institutions' provision of a specific preparation process for the end-of-life to help elderly residents at their end-of-life receive comfortable care, especially pain relief, which enables them to see their loved ones die with dignity and peace. Such care is the key that affects their willingness to trust and choose to let the dying elderly relatives receive institutional hospice care. It is recommended that institutions develop a complete evaluation form to provide suitable care activities that meet the needs of residents at the end of life, assist family members to participate in the end-of-life care of residents, and shorten the mourning period.

6. CONCLUSION

The development of the institutional hospice care model can help institutional dying elderly residents minimize their physical pain during the end of life, receive comfortable care, maintain dignity and peace, and successfully end a meaningful life.

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However, as the end-of-life care of institutions involves many aspects, the care model should continue to be applied to multiple institutions in the future, and continue to be modified to render the care model more practical and perfect to assist elderly residents in obtaining hospice care in institutions.

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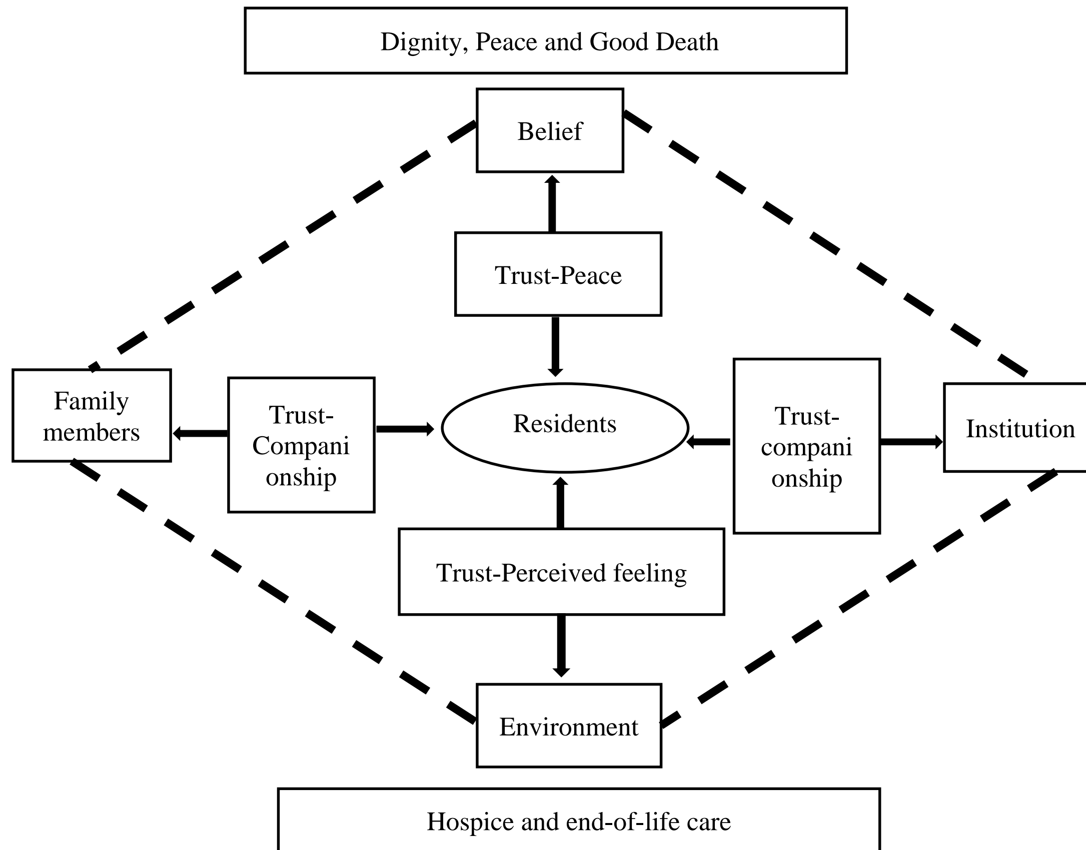

Figure 1. Institutional Hospice Care Model

Table 1. Care guidelines for Institutional Hospice Care

Admission or change of disease condition	Stage of coma	Stage of death
Meeting with family members to prepare a will	Cooperating with doctor, nutritionist, and caregiver to maintain supportive care for comfort and physiological symptoms	Confirming the time of death and informing doctor of such information to help issue the certificate of death
Choosing the location and method of death (Location: institution or hospital)	Closely monitoring vital signs	Taking care of the body and handling the funeral
Arranging an adequate environment and cultural considerations	Assisting family members and residents in visiting and accompanying the residents	Cooperating with social workers to provide family members with counseling
Deciding the location where the body will be sent	Implementing end-of-life care evaluation and religious intervention	Assisting in choosing and arranging funeral
Cooperating with social workers to provide family members with psychological counseling and support	Monitoring near-death signs	Social workers performing follow-ups on the counseling of family members after they return home