Palliative Care Needs Among People Living with Chronic Illness In Community: A Thai Cultural Religion Perspective

ความต้องการการดูแลแบบประคับประคองสำหรับผู้เจ็บป่วยด้วยโรคเรื้อรังในชุมชน: ในมุมมองศาสนาของวัฒนธรรมไทย

Jintana Artsanthia, Dr.P.H., จินตนา อาจสันเที๊ยะ, สด.[1]*
Somsri Sumet, Dr.P.H., สมศรี สุเมธ,สด.[2]
Supaporn Daodee, Ph.D., สุภาพร ดาวดี,ปร.ด.[3]
[1]*Associate Professor, Ph.D., Faculty of Nursing, Saint Louis College, Sathorn, Bangkok.*
[1]*รองศาสตราจารย์ ดร., คณะพยาบาลศาสตร์ วิทยาลัยเซนต์หลุยส์ เขตสาทร กรุงเทพฯ*
[2]*Lecturer, Ph.D., Faculty of Nursing, Saint Louis College, Sathorn, Bangkok.*
[2]*อาจารย์ ดร., คณะพยาบาลศาสตร์ วิทยาลัยเซนต์หลุยส์ เขตสาทร กรุงเทพฯ*
[3]*Assistant Professor, Ph.D., Faculty of Nursing, Saint Louis College, Sathorn, Bangkok.*
[3]*ผู้ช่วยศาสตราจารย์ ดร., คณะพยาบาลศาสตร์ วิทยาลัยเซนต์หลุยส์ เขตสาทร กรุงเทพฯ*

**Corresponding Author Email: jintana.a@slc.ac.th*

Received: March 23, 2020 Revised: May 13, 2020 Accepted: May 30, 2020

Abstract

This systematic review aimed to explore the Thai cultural perspectives of palliative care needs among people living with chronic illness. The literature reviewed the practice of palliative care with relevance to the religious and cultural perspectives of people living with chronic illness. People living with chronic illness need palliative care with consideration on cultural backgrounds and perspectives. Knowledge of cultural and religious backgrounds of people who have chronic illnesses is important in developing a trusting and supportive relationships among patients, family, and healthcare providers. So cultural perspectives in palliative care can enhance quality of care in nursing and quality of life of patients and their families.

Keyword: *Palliative care needs, Chronic illness, Community, Thai cultural religious of Buddhism, Christian, and Islamic perspectives.*

บทคัดย่อ

การทบทวนอย่างเป็นระบบครั้งนี้มีวัตถุประสงค์เพื่อศึกษาความต้องการการดูแลแบบประคับประคองในมุมมองศาสนาของวัฒนธรรมไทยสำหรับผู้เจ็บป่วยด้วยโรคเรื้อรัง จากการทบทวนวรรณกรรมในการดูแลแบบประคับประคองผู้เจ็บป่วยด้วยโรคเรื้อรังมีความเกี่ยวข้องกับมุมมองทางศาสนาและวัฒนธรรมของผู้คนในชุมชนเหล่านั้น สำหรับผู้เจ็บป่วยด้วยโรคเรื้อรังจำเป็นที่จะต้องได้รับการดูแลเอาใจใส่ ที่ควรพิจารณาถึงภูมิหลังและวัฒนธรรมของชุมชนนั้นด้วย ความรู้ความเข้าใจในด้านวัฒนธรรมและภูมิหลังของผู้เจ็บป่วยด้วยโรคเรื้อรังนั้นเป็นสิ่งสำคัญนำไปสู่การพัฒนาความไว้วางใจ และส่งเสริมสัมพันธภาพระหว่างผู้ป่วย ครอบครัว และทีมสุขภาพ ดังนั้นมุมมองศาสนาของวัฒนธรรมไทยในการดูแลแบบประคับประคองผู้ที่เจ็บป่วยด้วยโรคเรื้อรัง สามารถสร้างเสริมคุณภาพการดูแลด้านการรักษาพยาบาล และคุณภาพชีวิตของทั้งผู้ป่วยและครอบครัว

คำสำคัญ: *ความต้องการการดูแลแบบประคับประคอง โรคเรื้อรังในชุมชน มุมมองศาสนา พุทธ คริสต์ อิสลาม วัฒนธรรมไทย*

Introduction

Chronic diseases including heart disease, cancer, stroke, chronic respiratory diseases, end state kidney disease, diabetes and so on, which are the leading causes of death in the world, represents 63% of all deaths. Chronic diseases cause increasing numbers of deaths worldwide. Deaths due to dementias had increased more than doubled during 2000 and 2015, it was the 7th leading cause of global deaths in 2015 (World Health Organization, 2019). As today, the number of adults living with chronic illness have increased. Chronic diseases have impacted not only individuals' quality and length of life, but also on societies worldwide. (https://www.statista.com, 2016). Many studies found that palliative care can benefit chronic illnesses and conditions (Zhukovsky ,2019).

Global Trend of Chronic illness

Developed countries

Chronic diseases are the most common, costly, and preventable in all health problems in the U.S. There were 7 out of 10 deaths among Americans each year caused by chronic diseases. Heart disease, cancer and stroke accounted for more than 50% of all deaths each year. They were also leading drivers of the nation's $3.5 trillion in annual health care costs (Centers for Disease Control and Prevention, 2008). The number was projected to increase by more than one percent per year by 2030, resulting in an estimated chronically ill population of 171 million (National Vital Statistics Reports, 2018). The most common chronic conditions were high blood pressure, arthritis, respiratory diseases like emphysema, and high cholesterol level in blood. The problems from chronic diseases continued to be major causes of morbidity,

mortality, and health-care costs worldwide, which was a global health issue.

More than 50 million Americans under 65 years of age have some type of pre-existing condition (Kung, Hoyert, Xu & Murphy, 2008). Diabetes continues to be the leading cause of kidney failure, non-traumatic lower-extremity amputations, and blindness among adults, aged 20-74 (CDC, 2018). Four common causes of chronic diseases were health risk behaviors such as lack of physical activity, poor nutrition, tobacco use, and excessive alcohol consumptions. These are responsible for common illnesses, suffering, and early deaths related to chronic diseases. Palliative care in the United States, has grown tremendously. Historically, it had been predominantly delivered in an acute care setting. There were many different models within those settings evolved: continuing care, consultation, primary care, and unit based. The patients spent the majority of their time at home. The recent studies indicated good outcomes of palliative care. Literature demonstrates that, as with the inpatient services, these community programs come in many staffing matrices with different models of delivery and under many different monitors of palliative care. The innovative approach that community provided palliative care services to patients and their families outside an acute care facility. Referrals, staffing, care settings, and care processes that were established when the patient and family were placed at home (Robinson & Stacy,2005). A large number of factors have been identified for the underutilization of hospice care by ethnic minorities and greater utilization of inpatient settings by elderly minorities. (Groot,Vernooij & Verhagen,2007).

Similar to England, Chronic diseases linked to unhealthy lifestyles were costly the UK economy £21.6 bn a year in lost productivity, Occupational health, 2011. Margaret Chan, WHO Director General, said: “The rise of chronic non-communicable diseases presents an enormous challenge”. For some countries, it is no exaggeration to describe the situation as an impending disaster; a disaster for health, for society, and most of all for national economies. So many developed countries still cope with chronic diseases and try to solve these problems but less burdened than developing countries (Cynthia, 2006).

Developing countries

Chronic diseases were responsible for 50% of the diseases burdened in 23 high-burdened developing countries in 2005 and will cost $84 billion by 2015 if nothing has been done to slow their growth. (Cynthia,2006). India is undergoing rapid epidemiological transition as a consequence of economic and social changes. The pattern of mortality is key indicator for consequence of health effects but remains lacking of up-to-date, precise, and reliable statistics, especially in rural areas. Diseases of the cardiovascular system were the leading causes of mortality (32%), as similar to causes of deaths from ischemic heart diseases and stroke (Rohina et al.,2006). At the beginning of the third millennium, non-communicable diseases would be sweeping up the entire globe, with

increasing trends in developing countries, where the transition imposes more constraints to deal with the double burden of infective and non-infective diseases in a poor environment characterized by ill-health systems (Sakhuja & Sud, 2003). By 2020, it is predictable that these diseases will be causing seven out of every 10 deaths in developing countries (Boutayeb & Boutayeb , 2005).

Palliative care

There is an increasing incidence of chronic illnesses associated with long life. Chronic illnesses could impact on one's life and cause griefs. A fundamental paradigm shift in nursing is necessary to prepare professional nurses to provide quality care of chronic illnesses in the community. Palliative care is an approach that could empower quality of life for patients and their families to deal with life-threatening illnesses, through the process of health promotion and relief of suffering by means of early detection and impeccable assessment as well as treatment of pain and other problems, including physical, psychosocial and spiritual aspects (WHO, 2006). There are varieties of potential life interruptions and psychological distress when individuals are dealing with illnesses. Some older people encountermany health problems such as suffering from diseases and pain due to symptoms of the diseases. Elderly with chronic illness often need a caregiver for sustaining their quality of life. Quality of life is defined as the physical, psychological, social, and spiritual domains of health that are influenced by a person's experiences, beliefs, expectations, and perceptions (Scanlon, 2003; Merrison & Meier,2004).

Palliative care in Thailand

In 2005, the national palliative care network was established in Thailand and since then had made progress in both rural and urban. However, at that time in Bangkok, this network had not effectively linked with community organizations, such as home- based palliative care services. In Thailand, people live characteristically with single families from a survey study in Bangkok Thailand (Saint Louis College, 2018). The construction of family has changed from extended family to single family. This factor leads to the needs for palliative care and end of life care in order to support while coping with dying of family member at home. The majority (74%) of Thai people prefer dying at home surrounded by their close relatives until their last breath (Artsanthia,2011). Palliative care could empower physical, emotional, and spiritual supports during the advanced stage of diseases in order to improve quality of life. Many hospitals have established palliative care working groups and are establishing palliative and end of life care programs for their patients.

At present, there are palliative care settings in most hospitals including secondary care hospitals, but palliative care in health centers or health promotion hospitals in community level remain in need. They might be established in few settings depending on the interest of community nurses. In Thailand, the utilization of health volunteers could be beneficial to assisting

health care providers to follow up with people in the community. So that could be successful in establishing palliative care in community. Many community nurses are interested in palliative care because the society has changed to aging society. They expressed the needs to establish palliative care for their patients especially in chronic illnesses.

Physical Care Needs

According to pathophysiological changes in persons with chronic illnesses, the survey study from one (or more) community/communities of Bangkok found that Thai elderly had average body weight 60.91 kg. BMI (>25.0) 62.9%. The score of physical well-being was 6.89±2.58 (± SD) from 10. Many seniors suffering with chronic illnesses need health care providers to visit at home for resolving health problems. Some of them said "some days were good, some days were bad", which reflects issues of health problems and they needed help to relieve physicalproblems. The score of physical well-being =6.89±2.58, spiritual well-being = 7.90±2.09, Family well-being =7.94±2.19 and social and economic well-being =7.29±2.30 from 10 of all items. (Saint Louis College, Nursing Faculty ,2018).

Spiritual needs

Spiritual needs may vary depending on the philosophical bases on one's religion. In Thailand, 94.7% Buddhist, 4.6% Muslim, 0.8% Christian. In order to explore the differences among those three most prevalent religions in Thailand, a brief discussion was presented (Saint Louis College, Nursing Faculty, 2018).

Cultural perspectives in healthcare

The cultural backgrounds of people who have problems in chronic illness are important in healthcare in order to help develop trust and supportive relationship among patients, family, and healthcare providers. Since the last comprehensive review of the Health Belief Model (HBM), cultural perspective in healthcare has continued to be the focus of considerable theoretical and research attention. There are still many health beliefs and cultural perspectives that health care providers should know and be put into consideration in the use of palliative care. (Burles, Holtslander, Peternelj-Taylor, 2019).

Christianity

Christianity comprises three major branches: Roman Catholicism, Eastern Orthodoxy and Protestantism. There are diversities of doctrines and practices among three groups calling themselves Christian. Most Christians believe Jesus is the Son of God, who has become human and the savior of humanity. Christians commonly refer to Jesus as Christ or Messiah (Charles,2015). The Christian faith, known as Christianity, believes that Jesus is the Messiah prophesied in the Hebrew Bible. The foundation of Christian theology has expressed in the early Christian ecumenical creeds, which contain claims predominantly accepted by followers of the Christian faith. The professions state that Jesus suffered, died, was buried, and was resurrected from the death to open heaven to

those who believe in him and trust him for the remission of their sins (salvation) (Francis J. Sheed,1993). They further maintain that Jesus bodily ascended into heaven where he rules and reigns with God the Father. Most denominations teach that Jesus will return to judge all humans, living and dying, and grants eternal life to his followers. He is considered the model of a virtuous life, and both the revealer and physical incarnation of God. Christians call the message of Jesus Christ the Gospel ("good news").

According to their beliefs, Christians may not fear death because they can return to God and live with him for eternity in heaven. In the Roman Catholic, there are spiritual rituals in illness as well as a ritual for end- of- life. The priest acts as the spiritual leader in ritual for patients and families. Most Christians practice in as prayers and read the bible to request the good things for their life (Francis J. Sheed,1993).

Nurses who are responsible in providing palliative and end of life care for Christians should support patients and families by respecting their beliefs in religious practices at the time of illness and end-of-life. They need to be respectful and supportive of their traditional spiritual practice, particularly in relation to the sacrament that is practiced by the priest if available, at the time of death and dying.

Buddhism

In Buddhist beliefs, the important thing to help people accept reality are the four noble truths. They are the truth from Buddha (Buddhism,1996). First, suffering is common to all. Second, suffering has causes. Third, to end suffering, one must stop doing what causes suffering. Fourth, the path to end suffering where everyone can be enlightened. The Nature of suffering (or Dukkha) such as birth is suffering, aging is suffering, illness is suffering, death is suffering; sorrow, pain, grief and despair are suffering. Moreover, union with what is displeasing is suffering, separation from what is pleasing is suffering, not to get what one wants is suffering. The path leading to the cessation of suffering is the noble eight-fold path. It is composed of right view, right intention, right speech, right action, right livelihood, right effort, right mindfulness and right concentration (Buddhism,1996). According to this belief, many people in Buddhism can accept the process of life such as birth, aging, illness and death. When end of life is coming, palliative care can be integrated with religious belief leading to the strengthening of the soul to cope with difficulty in life and they can say thanks for the diseases for teaching them learn more and encounter with challenged things (Dan ,2002).

The practice in palliative care and Buddhism allows patients to do the following: pray to the Buddha to request good things in life, pay kindness to someone or animal related in suffering together, concentration practice, donate rice or money to the monk. Moreover, it is an important thing that when the end of life is coming, the nurse or the relative should act as the guiding holy route to pass away, to the new land or paradise for patients who are dying. Guide them the good thought, the good manner

which ever to do in the pasts and to recall to Buddha or monk. At this stage, if someone practices these beliefs in the right way, he/she will pass away peacefully.

Islam

Muslims believe that God is an incomparable one. The purpose of life is to worship God. Islamic laws are touch on every aspect of life and society, encompassed everything from banking and warfare to welfare and the environment (The New Encyclopedia of Islam, 2003). Religious practices include the Five Pillars of Islam, which are five obligatory acts of worship. The Five Pillars of Islam (Gardet, 2003) the shahadah, which is the basic creed of Islam that must be recited under oath. Salah, or ritual prayer is a second pillar, which must be performed five times daily. Salah is compulsory but flexibility in the specifics is allowed depending on circumstances. Sawm a third pillar, is fasting during the month of Ramadan. Muslims must not eat or drink (among other things) from dawn to dusk during this month, and must be mindful of their sins. Zakat, or alms-giving to help the poor or needy is the fourth pillar. The fifth pillar is Hajj, which is the pilgrimage during the Islamic month of Dhu al-Hijjah in the city of Mecca (Glasse, 2003).

Implications for palliative care in Islam faith include the facilitating the environment for prayer, allowing family and relatives to visit and pray at the end of life. It means that Islam can be protect them from evil. Care givers also need to be aware of the belief in burial within 24 hours after death.

Palliative Care Model in cultural perspective

There were some reported studies, one of them was the study of home-based palliative care found that the activities in home based palliative care composed of 4 steps: 1. Develop relationships; explaining objectives, assessment of symptoms, including physical, psychological and spiritual. This process facilitated communication among families, persons with ESRD and health care providers. 2. Develop understanding; treatment and support from symptoms, suggestions for palliative care needs at home. This process aimed to determine symptom management for people living with ESRD. 3. Develop mindfulness; explain more in detail the process of palliative care and assess acceptance of relatives and patients. This process aimed to determine psychosocial support needs and processes of care. 4. Develop acceptance; provide follow up to assess psychological need of people, uncertainty of life, satisfaction, and quality of life at home. This process aimed to support the dying at home. Moreover, the process of the end of life before death in people living with ESRD include 3 cycles: cycle 1: Karma dreams and the moral dreams, cycle 2: Suffering from the uncomfortable symptoms and trying to do good karma, and cycle 3: A peaceful death (Artsanthia, Barbara, Chaiphibalsarisdi, Nitayasuddhi, & Triamchaisri, 2011).This process leads to the patients' acceptance of the way of life by understanding the changing of the cycle that occurs in one's life.

Conclusions

Palliative care is a person-centered approach concerned with physical, psychosocial, and spiritual care in a progressive disease. Palliative care must include an awareness and respect of person's religious beliefs because spiritual and culture cannot be separated. To achieve good quality palliative care, community and strong family support are necessary along with a strong health structure provider. So palliative care requires a public health provider to ensure a well-integrated health care system to chronic illness achieve quality of life of people in community.

References

Artsanthia, J. (2011). *Development of home-based palliative care for people who living with end stage renal disease*. (Doctoral dissertation). Mahidol university, Bangkok.

Artsanthia, J., Barbara, E.M., Chaiphibalsarisdi, P., Nitayasuddhi, D., & Triamchaisri S. (2011). Exploring the palliative care needs of people living in Thailand with End stage renal disease: A pilot study. *Journal of hospice & palliative care nursing, 13*(6), 403-410.

Boutayeb,A., & Boutayeb, S. (2005). The burden of non communicable diseases in developing countries. *International journal for equity in health, 4*(1), 2.

Buddhism. (1996). *A Brief Introduction.* Developing Virtue Secondary School.Burlingame, California: Buddhist Translation Society. Retrieved May 28, 2019 from https://www.books.google.co.th/books?id=p9hl_NfbkCUC&pg=PP5&lpg=PP5&dq=Buddhism.

Burles, M., Holtslander, L., & Peternelj-Taylor, C. (2019). Palliative and Hospice Care in Correctional Facilities: Integrating a Family Nursing Approach to Address Relational Barriers. *Cancer Nursing.*

Centers for Disease Control and Prevention. (2008). National diabetes fact sheet: 2005. Atlanta (GA): US Department of Health and Human Services, Centers for Disease Control and Prevention; 2005.

Briggs, C. L. (2015). Rethinking Psychoanalysis, Poetics, and Performance. *Western Folklore journal,* 74(3/4), 245.

Goh, C. (2006). The gap between research in developing and developed countries in Asia. *Palliative Medicine,* 20(3), 240-241.

Glassé, C., & Smith, H. (2003). *The new encyclopedia of Islam (Revised, illustrated ed.). Rowman Altamira* (p. 302). ISBN 0-7591-0190-6.

Dan, L. (2002). Buddhist Phenomenology. *NY: Routledge Curzon.*

Sheed, F. J. (1978). *Theology & Sanity.* A&C Black.

Gardet L. (2003). "Qiyama". *Encyclopaedia of Islam Online.* Retrieved September 23, 2010 from http://www.books.google.co.th/books?id=lhTr-4OhMlsC&pg=PA696&dq=Gardet+L.+(2003).

Groot, M. M., Vernooij-Dassen, M. J., Verhagen, S. C., Crul, B. J., & Grol, R. P. (2007). Ob stacles to the delivery of primary palliative care as perceived by GPs. *Palliative medicine,* 21(8), 697-703.

Kung, H. C., Hoyert, D. L., Xu, J., & Murphy, S. L. (2008). Deaths: final data for 2005. *Natl Vital Stat Rep, 56*(10), 1-120.

Meier, D. (2005). Palliative care as a quality improvement strategy for advanced, chronic illness. *Journal for Healthcare Quality,* 27(1), 33-39.

Rowan-Robinson, M., Babbedge, T., Surace, J., Shupe, D., Fang, F., Lonsdale, C., ... & Xu, K. (2005). Spectral energy distributions and luminosities of galaxies and active galactic nuclei in the Spitzer wide-area infrared extragalactic (SWIRE) legacy survey. *The Astronomical Journal,* 129(3), 1183-1197.

Joshi, R., Cardona, M., Iyengar, S., Sukumar, A., Raju, C. R., Raju, K. R., ... & Neal, B. (2006). Chronic diseases now a leading cause of death in rural India—mortality data from the Andhra Pradesh Rural Health Initiative. *International journal of epidemiology,* 35(6), 1522-1529.

Sakhuja, V., & Sud, K. (2003). End-stage renal disease in India and Pakistan: burden of disease and management issues. *Kidney International,* 63, S115-S118.

Scanlon, C. (2003). Ethical Concerns in End-of-Life Care: When questions about advance directives and the withdrawal of life-sustaining interventions arise, how should decisions be made?. *AJN The American Journal of Nursing,* 103(1), 48-55.

Saint Louis College, Nursing faculty. (2018) A *Survey study in community nursing of nursing student in academic year 2018.* Report study of Health center 3, Bangkok.

World Health Organization. (2002). *National cancer control programs: policies and managerial guidelines.* World Health Organization.

World Health Organization. (2019). *Chronic diseases and health promotion.* Retrieved January 22,2020 from https://www.who.int/chp/about/integrated_cd/en/

Zhukovsky D. (2019). *Primer of Palliative Care.* 7th Edition. American Association of Hospice and Palliative Medicine. ISBN 9781889296081.