

Primary Palliative Care Service in Thailand and Bali, Indonesia

การจัดบริการดูแลแบบประคับประคองปฐมภูมิในไทยและบาหลี อินโดนีเซีย

บทความวิชาการ

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บทคัดย่อ

ทุก ๆ ประเทศมีความตระหนักเกี่ยวกับคุณภาพชีวิตของประชาชนที่เจ็บป่วยด้วยโรคเรื้อรังรักษาไม่หายขาดและจำนวนผู้ป่วยที่เพิ่มขึ้นเนื่องจากการเข้าสู่การเป็นสังคมผู้สูงอายุ การดูแลแบบปฐมภูมิเป็นคำที่ใช้ในด้านการจัดการของทีมสุขภาพเป็นจุดแรกของการดูแลและปรึกษาทางสุขภาพ ผู้ดูแลในระบบปฐมภูมิมีบทบาทสำคัญต่อการจัดการดูแล แต่มักจะขาดแคลนในกระบวนการของการดูแลและแหล่งทรัพยากรที่จะทำให้การดูแลแบบประคับประคองมีประสิทธิภาพ เช่นในไทยและบาหลี อินโดนีเซีย การสาธารณสุขเริ่มขยายบทบาทเข้าสู่การสร้างศักยภาพในการดูแลที่จึ่งมีส่วนร่วมในการดูแลภาวะใกล้ตาย การสูญเสียซึ่งรวมอยู่ในการดูแลแบบประคับประคองในบทบาทของวิชาชีพ ประเทศไทยและบาหลีมีความแตกต่างทางศาสนาแต่มีหลักการจัดการพยาบาลแบบประคับประคองแบบเดียวกัน สำหรับในชุมชนการสาธารณสุขริเริ่มพัฒนาระบบบริการแบบประคับประคองจากท้องถิ่นเพื่อลดความทุกข์ทรมานจากความเจ็บป่วยเรื้อรัง ทีมการดูแลแบบประคับประคองปฐมภูมินี้ช่วยครอบครัวและผู้ป่วยในการกระตุ้นความรู้สึกนึกคิด ลดความวิตกกังวล และความกลัว ดังนั้นทีมการดูแลควรทราบและอภิปรายได้ว่าอะไรคือความต้องการและการตอบสนองต่อปัญหาเหล่านั้น ด้วยการประเมินและสนองความต้องการที่เหมาะสม ซึ่งเป็นการวางแผนการดูแลแบบประคับประคอง

การดูแลประคับประคองปฐมภูมิในชุมชนมีวัตถุประสงค์ในการประสานการดูแลระหว่างโรงพยาบาลกับชุมชน สำหรับประเทศไทย ได้เริ่มจากโรงพยาบาลและผลักดันสู่ชุมชนในระดับการดูแลขั้นปฐมภูมิ ส่วนบาหลีการดูแลแบบประคับประคองเริ่มจากโรงพยาบาลประจำจังหวัดและยังอยู่ในความพยายามทำความเข้าใจในหลักการของการดูแลแบบประคับประคองปฐมภูมิและกระจายสู่ชุมชน แต่ยังคงขาดพยาบาลชุมชนที่ผลักดันการดูแลแบบประคับประคองจึงจำกัดการดูแลอยู่ในโรงพยาบาล สิ่งที่จะทำให้บาหลีประสบความสำเร็จในการดูแลแบบประคับประคอง คือการมีความเชื่อด้านจิตวิญญาณที่เข้มแข็ง คือการมีความเชื่อด้านจิตวิญญาณที่เข้มแข็ง ถ้าทีมสุขภาพสามารถเชื่อมต่อการดูแลเข้ากับความเชื่อทางศาสนาของชาวบาหลีจะทำให้การดูแลแบบประคับประคองประสบความสำเร็จเป็นอย่างดี

คำสำคัญ : การดูแลแบบประคับประคองปฐมภูมิในไทย, การดูแลแบบประคับประคองปฐมภูมิในบาหลี

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Abstract

Every country concerns about quality of care for people who living with chronic illness and incurable disease that are increasing due to aging society. Primary care is a term used for the activity of a health care provider who acts as a first point of consultation for all patients. Primary care professionals play a central role in optimizing available care, but they often lack the processes and resources to do this effectively such as in Thailand and Bali, Indonesia. Public health initiatives also build or enhance a community's capacity to share the responsibility for dying, loss and palliative care in partnership with formal, professional care. Thailand and Bali is different religious but it has the same concept in palliative care setting. Community and public health initiatives in palliative care are joining to develop palliative care services in partnership with their local communities to relief suffering. Primary palliative care teams help families and patients to evolve their thoughts, feelings, anxieties, and fears so that they can verbalize them, discuss what needs to be discussed, find answers to those problems that have solutions, get reassurance when it is appropriate, and develop a plan of action for problems.

Primary palliative care in community has objective to link between hospital and community. In Thailand, palliative care occurs in hospitals and attempts to extend service to community in primary care level. In Bali, palliative care launch in province hospitals and the next attempt to making understanding of the nurses in the concept of primary palliative care but they lack of community nurses who will work for primary palliative care. One thing of Bali to success in primary palliative care is strong in their belief if the health care providers can link between health and psychosocial of Balinese.

Keywords: Primary palliative care in Thailand, Primary palliative care in Bali

Introduction

Primary care has a vital role in palliative care. In most developed countries more people die in hospital than at home, although substantially more people would prefer to die at home. Over 90% of all patients with cancer spend sometimes in hospital during the last year of life, while 55% die in hospital and 17% die in a hospice. (Froggatt, K., Payne, S. A. 2006). The desired place of death may change with altered circumstances, the most obvious being difficult symptoms and lack of practical help at home. Patients who are frightened, insecure, or lack confidence in their support network are more likely to seek urgent admission to hospital or hospice. Equally, if informal carers are physically or mentally tired they are more likely to seek admission, even when death is imminent.

Community health nurses (CHN) have a vital role to play in the creation of organizations and systems, which promote equity and health central to the goals of the public health agenda. Furthermore, CHNs work with communities in identifying and addressing their problems. This requires staff not only to work in partnerships but also to break down boundaries by providing integrated care within health and social care teams and participating fully in health impact assessment.

Primary care and palliative care service

Defining of primary care refer to the care provided by certain clinicians. Some proposed legislation. Some experts and groups have included nurse practitioners and physician assistants. A set of

activities whose functions define the boundaries of primary care-such as curing or alleviating common illnesses and disabilities; A level of care or setting, an entry point to a system that includes secondary care by community hospitals and tertiary care by medical centers; A set of attributes, definition care that is accessible, comprehensive, coordinated, continuous, and accountable or that is characterized by first contact, accessibility, longitudinally, and comprehensiveness.

Palliative care (WHO, 2006) is an approach that improves the quality of life of patients and their families facing the problem 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. Palliative care: provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patients illness and in their own bereavement; provide the relative counseling after death uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated; will enhance quality of life, and may also positively influence the course of illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Palliative care arose out of the change from acute to chronic causes of death and the emphasis of health care on improving quality of life. In the

United Kingdom, specialist palliative care is provided mainly for cancer patients through hospices and support teams, which have grown rapidly in the last 30 years. Single sites and more recently several units have demonstrated their effectiveness, acceptability and efficiency. However, the majority of people who die will not receive these services but will receive much of their care in hospital, nursing home and community settings. The growing numbers of people who are likely to die from HIV/AIDS and the growing numbers of older people make it important that palliative care becomes more integrated with hospital, community and general practitioner services. Palliative care should become a gradually increasing part of care from diagnosis to death, rather than being concerned only with the terminal phase. A palliative care component and appropriate standards could be included in the needs assessment and the contracts for many hospital and community services. In research on new treatments, particularly for cancer and HIV/AIDS, palliative aspects should be measured along with survival and the usually fairly basic estimates of quality of life. Hospices, and in particular support teams and day care, require further evaluation if they are to extend their role to providing care for the younger people with HIV/AIDS and the older people who are dying from chronic diseases such as cardiovascular disease (Ellershaw, J. & Wilkinson, S., 2003)

Palliative care services are not exempt from these pressures. Facing the consequences of a progressive, life limiting illness can exhaust the physical and emotional resources of patients, primary carers and their families, and indeed can also deplete those of the health care professionals who care for them. It is important in a caring and compassionate society, that health and social support systems are developed to ensure that the needs of all these people can be appropriately supported.

Evidence suggests that the main reasons for people failing to achieve a home death are carer fatigue and inadequate provision or deployment of palliative care services. Planning the care of patients who have been diagnosed with incurable cancer, including recording the patient's wishes about his/her end-of-life care can be assisted by the use of a mechanism. Palliative care is an approach that improves the quality of life of patients and their families facing the problem 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 (Froggatt, K., 2001).

The provision of care from the community palliative care service takes account of the uniqueness of the individual and their culture, is patient centered and designed to meet the changing and complex needs of patients and carers. However, little published research about evaluating palliative care provision in the community and more research is required. In addition, there has been increasing concern about how to extend palliative care to patients with terminal disease other than cancer. As with both hospice and hospital-based palliative care, much of the care provided by primary care teams is directed at patients with cancer. As a result patients dying of non-malignant disease often have little or no access to palliative care. Providing care for other chronic terminal conditions may be more problematic because it may be difficult to establish an exact prognosis or identify the needs of such patients. Palliative care services must also recognize and respond to community need and expectation, including those of disadvantaged, culturally and linguistically diverse groups. The success of community and public health education about palliative care has meant that more people now expect to be able to access palliative care. Palliative care services are under pressure to accept increasing

numbers of patients as community awareness grows, and express concern about their capacity to meet projected demand over the coming decade.

Challenging in Primary Palliative Care Service

Community and public health initiatives bring about changes to social settings and attitudes. They are designed to be implemented in creative and supportive environments outside direct services. Public health initiatives also build or enhance a community's capacity to share the responsibility for dying, loss and palliative care in partnership with formal, professional care. Although death is inevitable, many of the social, psychological and spiritual issues that should discuss. Community and public health initiatives in palliative care are joint programs developed by palliative care services in partnership with their local communities to reduce these possible harms. Primary care teams should help families and patients to evolve their thoughts, feelings, anxieties, and fears so that they can verbalize them, discuss what needs to be discussed, find answers to those problems that have solutions, get reassurance when it is appropriate, and develop a plan of action for problems that have no easy solution and are likely to worsen. Primary care professionals play a central role in optimizing available care, but they often lack the processes and resources to do this effectively.

Managing a patient at home requires not only an accurate assessment of the patient and his or her illness, and support network but also an assessment of the patient's home. This may require an occupational therapist or physiotherapist to advise on the need for aids and, if necessary, modifications to the home. Forward planning is crucial, and much effort has to go into the general structure of care, which must be individualized for each patient. While primary care teams can systematically work through the aspects noted above, there is no automatic

formula for all cases. Stressed families caring for a dying patient are unlikely to have their thoughts well organized at the time of a first meeting. There is a rapidly increasing number of older people living and dying in care homes. The relative isolation of nursing care homes from the development of palliative care, the poor retention and recruitment of staff, and the lack of medical cover, hinder the provision of quality end-of-life care. End-of-life care strategies internationally highlight the benefit of using tools to help improve end-of-life care in care homes (Hockley, J., 2006).

Some studies found that community nurses and members of the public from the Republic of Ireland perceived that community nurses do not have the skills to take a lead role in the commissioning of services, that they require intensive training to take on such roles, and those who do should have equal remuneration with GPs who are involved in service commissioning. Recommendations are offered in the form of action points to guide future practice and policy (McCann, S., Ryan, AA. & McKenna, H., 2005). Moreover, Robinson, L & Stacy, J. (2005) reviewed the status of palliative care in the community focusing on setting practice guidelines for primary care teams. Developing multidisciplinary as opposed to medical guidelines for palliative care allows primary health care teams to create standards that are acceptable to them and stimulates individuals within the teams to accept responsibility for initiating the change necessary for more effective care. The process of facilitating teams to discuss their work allows for recognition and respect of individuals' roles and more importantly provides shared ownership, an important contributory factor in the implementation of guidelines.

Consequently, this article seeks to establish whether there is a need for palliative care for patients with chronic terminal conditions or non-malignant disease, and the challenges of identifying and meeting

such a need. The intention is to provide data to enable improvement in the provision of palliative care in the community, by identifying and disseminating good practice and highlighting any barriers to good practice which may exist and suggest ways to overcome these from independent role of community nursing. So the model to set primary care in palliative care was following: (Artsanthia, J., 2012)

Palliative care implementation

1. Develop relationship;
Nursing care: explain objective, assessment symptom, psychological and spiritual
2. Develop understanding;
Nursing care: symptom management and support with palliative care concept at home and support psychological and spiritual with mind fullness meditation.
3. Develop mindfulness;
Nursing care: explain more in detail of palliative care and assess acceptance of relative and people living with end stage renal disease, unfinished business.
4. Develop acceptance;
Nursing care: follow up; assess psychological need of persons with end stage renal disease and uncertainty of life how to prepare until the last breath and bereavement care.
5. Evaluation of satisfaction;
Nursing care: evaluated all the process to assess the quality of life at home and satisfaction of palliative care nursing service.

Primary palliative care concept:

Primary palliative care concepts should compose of assessment and management of Pain and Symptoms with people who facing life-threatening conditions. In addition, health care providers in primary care can provide much-needed support by

educating the family about what to expect of illness. Health care professionals attending to people facing life-threatening conditions must be willing and able to discuss the possibility of death, the potential for physical and emotional suffering, and the strategies for its prevention and over treatment. Developing palliative care services in primary care is essential for realizing the expectations of dying people. Primary care professionals have the potential and ability to provide end of life care for most patients, given adequate training, resources, and, when needed, specialist advice.

Emotional and Spiritual Needs are important for palliative care. Thus, health care providers who working in community with life-threatening illness and their families must possess fundamental knowledge to support emotional and spiritual needs of people with life threatening to live with quality of life in their environment.

Bereavement Care steps divided in pre-bereavement to support and educational program for family, with a particular emphasis on psychological interventions to address emotional, social, bereavement and spiritual issues. The death of the person being cared for inevitably means that medical and social care support is immediately withdrawn. The next, bereavement care is the process of caring the parent after losing the one who loved. In this process related with culture and grief that health care providers should learn more in detail especially in religious practice when doing advice to family. Primary palliative care will be improved the quality of life (QOL) of people with a terminal illness in physical and psychological symptoms.

Primary Palliative Care Service in Thailand

Public Health is the organized effort of society to protect and improve the health and well-being of the population through health monitoring,

assessment and surveillance, health promotion, reducing inequalities in health status, prevention of disease, injury, disability and premature death, and protection from environmental hazards to health. Health, social, and palliative care services are continuing to fail many people with progressive chronic illnesses in whom death may be approaching, reflecting a failure to think proactively and holistically about their care. Prognostic paralysis has been described, whereby clinicians of patients with uncertain illness trajectories prevaricate when considering end of life issues. This is done through an appropriate balancing of the rights and responsibilities of individuals and organizations and the responsibility of government to protect and promote health (Appleton, J., 2000).

In Thailand, primary care is a term used for the activity of a healthcare provider who acts as a first point of consultation for all patients. Generally, primary care physicians or nurse practitioners or public health nurses or community nurses are based in the community, as opposed to the hospital. Primary care teams must maintain a role as gatekeepers to care, not just for referrals to specialist centers but also for referrals to specialist teams in the community. Timing of referral is an important, and, while referrals should be made early rather than late, there should be explicit agreement on the extent of involvement, including responsibility for counseling and emotional support for patient and family, community nurses do not have the skills to take a lead role in the commissioning of services, that they require intensive training to take on such roles, and those who do should have equal remuneration and who are involved in service commissioning.

Community health nurses or nurse practitioners initiative also build or enhance a community's capacity to share the responsibility for dying, loss and palliative care in partnership with formal,

professional care and informal for palliative care. Community and public health initiatives in palliative care are joint programs developed by palliative care services in partnership with their local communities to reduce these possible harms. The great majority of people who live with a life limiting illness spend most of their time - not in treatment centers or in the cradle of direct service provision but at home with their primary carer, friends, co-workers or family. Some spend their time in nursing home facilities or in remote indigenous communities, while others are itinerant. Public health initiatives send targeted messages to the widest number of settings to reach those who live with a life limiting illness, dying, loss or grief in settings outside conventional family homes and acute care settings. There is a model of home based palliative care for people in community that composed of 4 steps in developing relationships, understanding, mindfulness, and acceptance (Artsanthia, J., 2012). Moreover, many community hospitals and health promotion hospitals in Thailand have linked and set palliative care that they developed by using interdisciplinary team, case management, complementary nursing until good death at home. This study was congruent with the study of Scott, A. (2004) examined the development of developing primary palliative care found that people with terminal conditions should be able to die at home with dignity. Developing palliative care services in primary care is essential for realizing the expectations of dying people. Primary care professionals should have the potential and ability to provide end of life care for most people who living with chronic illness and end of life at home by giving adequate training, resources, and, when needed, specialist advice. So the roles of community nurses in primary palliative care are assess suffering people with chronic illness, manage pain and symptom control with many technics in non-pharmacology or pharmacology, coordinate with interdisci-

plinary team, develop care plan for clients and family, provide facilities in supporting palliative care at home.

Primary Care in Palliative Care Service in Bali

In Indonesia, there are 33 provinces. Bali is one of the provinces. Each province consists of some regency. Every regency divided into some districts, one district has some villages. Bali has more than 500 villages. In Bali, after village is Banjar, Banjar is the lowest level of community. The first level of health facility is Public Health Centre (Puskesmas). Public Health Center is institution that is responsible to provide health services to first degree and it is in the mids of the community as the first institution that provide primary health services.

Every public health center has a basic health programs such as (1) health promotion, (2) environment health, (3) health of mothers, children, and family plan, (4) community nutrition improvement, (5) prevention and combat of infectious diseases, and (6) medication.

Primary care in Bali is a good system. The primary care launch from public health center and the system in the health center of the village compose of supportive health center and integrated health post. One thing that sounds like problem is lacking of public health or community health nursing to active service for community. Most of the nurses who working in the health center are midwifery nurses so in Bali tries to set palliative care in hospital and the policy has extend to community. This policy might have problems in implementation because of lacking supporting team to work in active service for community.

Indonesia has a regulation regarding palliative care. The regulation was established in 2007. According the regulation, palliative care is conducted in five provinces that located in Jakarta, Yogyakarta,

Surabaya, Denpasar and Makasar. All the places implement the palliative care in province hospitals. In Bali (Denpasar City), the palliative care is performing in Sanglah Hospital. The hospital has a team to conduct palliative care. Palliative care was set as the team composed of the medical doctors, nurses, social workers. The model of care is not clear. Everything depends on religious practice. The nurses allow people and family to do many things from their needs. The strengthening system to set palliative care in Bali has the trend to success if Bali can set the public health nurses or community health nurses work in community not only most midwifery work for passive service in health center. Bali is the land of God and believes if health care providers can integrate the health care and religious practice to set palliative care for community following understanding the cultural backgrounds of patients is fundamental to develop the trust and supportive relationship between patient, family and healthcare providers. Karma or the consequences of one's actions or behaviors are influent the circumstances of life and may have cause of illness. This concept is the same as in Thai belief. So it is easier for doing or practices something to solve their problem in belief. Most Bali is Hinduism. The goal of Hinduism is to free the soul from endless incarnation and suffering. The end of the life is the result of karma or actions of individual in this present life and the accumulation of actions from the past lives.

Consequently, Thai and Bali are similar in their belief. For community, in Bali should set the health care system from passive service in health center to active service for setting primary palliative care for developing quality of life of people who living with chronic illness. Moreover, in Bali, they set mobile clinic to service in community as well. This is a good system. Most of the team should set multidisciplinary team for service primary palliative

care. But in Bali, the health care system lacks of community health nurses to do the responsible in health promotion, prevention, curative, rehabilitation. There are health volunteers in Bali but lacking of training primary palliative care for community. This is a gap that they should work more benefit for community because of living in community as well. So the trend to set primary palliative care in Bali is possible if they can set community nurses and training health volunteers because they have many facilitators such as policy, strong belief in religion.

Finally, primary palliative care service planning framework should provide a collaborative inclusive model that incorporates care provided by primary and specialist providers. It describes the relationships and coordination of care between the multiple providers and service levels on a population basis. The model should drive by the hierarchy of people in community, primary carer and family needs, and attempts to align services to most appropriately, effectively and efficiently meet those needs. Within the model, formalized links between generalist and specialist health care providers will ensure all people with a life limiting illness have a right of access to services appropriate to their particular needs. It is also expected that, ultimately, better use of resources, improved quality of care and improved demonstrable outcomes will be achieved as a consequence of the implementation of the framework. In addition, it is anticipated that improved coordination of care, better relationships between care providers and clearer role delineation will result from implementation.

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