THE STUDY OF PSYCHOMETRIC PROPERTIES OF THE QUALITY OF LIFE IN LATE-STAGE DEMENTIA (QUALID) SCALE THAI VERSION IN TERMINALLY ILL PATIENTS: PILOT STUDY IN ONE MEDICAL SETTING

MUTITA SUKTHAM

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ABSTRACT

This research had the primary objectives to translate the quality of life in late-stage dementia (QUALID) scale into Thai and study the psychometric properties of the translated version in terms of validity and reliability. The study was conducted on terminally ill patients who were admitted to the medical wards at Golden Jubilee Medical Center, Mahidol University; whereby data were collected from a total of 30 caregivers who were selected by means of purposive sampling. The study was performed in two stages: 1) The QUALID scale was translated into Thai and thereafter examined for content equivalence, and 2) The Thai version of QUALID scale was examined for reliability by using the internal consistency method.

The Thai version of QUALID scale was reviewed by an expert, specifically the developer of the instrument. The results indicate that there is content equivalence between the original and Thai version. In addition, upon assessment of the internal consistency reliability, it is evident that the Thai version of QUALID scale has a moderate level of internal consistency (Cronbach's $\alpha = 0.627$). Accordingly, this study suggests that the Thai version of QUALID scale has content equivalence with the original version, as well as an acceptable level of reliability.

KEY WORDS: THAI VERSION OF QUALID SCALE / TERMINALLY ILL PATIENTS / PSYCHOMETRIC PROPERTIES

70 pages

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การศึกษาคุณสมบัติการวัดของแบบประเมิน The quality of life in late-stage dementia (QUALID) ฉบับภาษาไทย ในผู้ป่วยระยะท้าย : การศึกษานำร่องในสถานพยาบาลแห่งหนึ่ง

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บทคัดย่อ

การวิจัยครั้งนี้มีวัตถุประสงค์เพื่อ แปลแบบประเมิน The quality of life in late-stage dementia (QUALID) เป็นภาษาไทย และศึกษาคุณสมบัติการวัดทั้งในด้านความตรงและความเที่ยง โดยทำการศึกษาในกลุ่มผู้ป่วยผู้ใหญ่ระยะท้ายที่รับไว้ในหอผู้ป่วยศูนย์การแพทย์กาญจนาภิเษก มหาวิทยาลัยมหิดล ทำการเก็บข้อมูลจากผู้ดูแลผู้ป่วย จำนวน 30 คน ทำการคัดเลือกกลุ่มตัวอย่างแบบเจาะจง การดำเนินการวิจัยแบ่งเป็น 2 ระยะ คือ 1) ทำการแปลแบบประเมิน QUALID เป็นภาษาไทยและตรวจสอบความตรงเชิงเนื้อหาของแบบประเมิน และ 2) ทำการตรวจสอบความเที่ยงของแบบประเมินโดยวิธีการตรวจสอบความสอดคล้องภายใน

ผลวิจัย พบว่า แบบประเมิน QUALID ฉบับภาษาไทย มีความตรงเชิงเนื้อหา โดยผ่านการตรวจสอบการแปลจากผู้เชี่ยวชาญซึ่งเป็นเจ้าของเครื่องมือ และจากการตรวจสอบความเที่ยงของแบบประเมินโดยการหาความสอดคล้องภายใน พบว่า แบบประเมินมีความสอดคล้องภายในอยู่ในระดับปานกลาง (Cronbach's $\alpha = 0.627$) การศึกษาครั้งนี้แสดงให้เห็นว่า "แบบประเมิน QUALID ฉบับภาษาไทย" มีความตรงเชิงเนื้อหาและมีความเที่ยงอยู่ในเกณฑ์ที่ยอมรับได้

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CHAPTER I
INTRODUCTION

Significance of the Study

The World Health Organization (WHO) reported that, in 2000, approximately 12% of deaths worldwide were attributable to cancer, and 80% of cancer patients in developing countries were in terminal phase before receiving diagnosis [1]. In addition, the rate of cancer is forecasted to increase by 50% to 15 million new cases by 2020. According to the statistics in 2012, cancer was the leading cause of death in Thailand, followed by cardiovascular disease and cerebrovascular disease. It is anticipated that chronic diseases such as cancer, cardiovascular disease, and diabetes mellitus will be the primary causes of death in the future [2]. It is also apparent that approximately half of patients suffering from these illnesses died at home due to high cost of treatment. Likewise, the majority of terminally ill patients have to endure the intractable pain of treatment, or even suffer from multiple symptoms due to inaccessibility of treatment.

At present, a variety of methods have been developed to treat patients with chronic diseases, whereby palliative care is considered to be one of the effective treatment methods and has been gaining popularity in the health care industry. Palliative care is essentially an interdisciplinary approach to treatment of life-limiting illnesses that emphasizes physical, psychological, social, and spiritual aspects. It is provided by a team of doctors, nurses and other specialists who work with both the patient and family. Patients will not only receive treatment for their respective illness but also emotional and spiritual support. The goal of palliative care is to optimize patients' quality of life to ensure that they are kept comfortable and pain-free in their final stage of life, as well as providing emotional support to family members in coping with bereavement [3]. Although hospices for terminally ill patients have begun to emerge in Thailand, there is still a low level of public awareness. According to the Quality of Death Index rankings prepared by Dr. Cynthia Goh, Chairman of the Asia

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Pacific Hospice Palliative Care Network, Thailand is still in the initial stage of developing palliative care [4].

Quality of life (QOL) is the primary indicator of health status or effects of illnesses on patients' capacity and can further be used to assess the effectiveness and outcomes of treatment. Since QOL can be defined in many different ways depending on the context, a variety of concepts of QOL have been constructed based on multiple frameworks, each of which serves different purposes and employs different methods. The concepts of QOL that have been widely adopted can be classified into two groups: (1) Health-related quality of life (HRQOL), which emphasizes the impact of health conditions, such as illnesses and disabilities, on QOL, whereby the Medical Outcomes Study Short Form (SF-36) and the Nottingham Health Profile are among the most common instruments employed in the assessment of HRQOL; and (2) Holistic quality of life, which accentuates a comprehensive array of fundamental factors that have an influence on QOL and does not primarily focus on illnesses or symptoms. Indeed, a wide range of instruments associated with the assessment of holistic QOL have been continually developed, such as the World Health Organization Quality of Life Questionnaire-100 (WHOQOL-100), the World Health Organization Quality of Life Questionnaire-BREF (WHOQOL-BREF), and the Integrative Quality-of-Life (IQOL) meta-theory [5]. In general, the assessment of QOL is conducted through the use of self-report instruments, which are applicable to healthy individuals or conscious patients with the ability to communicate and respond. Alternatively, in the case of terminally ill patients who are in a minimally conscious state and have limited communication abilities, different approaches such as observational instruments will need to be adopted in the assessment of their QOL.

The quality of life in late-stage dementia (QUALID) scale was developed by Myron F. Weiner et al. to assess the QOL of patients with Alzheimer's disease or late-stage dementia. These patients are predominantly dependent on caregivers, and their communication abilities are gradually diminished to such an extent that they can no longer communicate. Despite their limited syntactic abilities, patients with late-stage dementia can typically understand words and respond by means of expressing their emotions [6]. Hence, the QUALID scale encompasses dementia-specific questionnaire with a one-week window of observation conducted by primary

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caregivers. The questionnaire consists of 11 items, which are rated by frequency of occurrence on a five-point scale. Scores are summed to range from 11 to 55, wherein lower scores reflect higher QOL [7]. It is apparent that the QUALID scale is useful for assessing the QOL of patients with limited communication abilities, which is commonly found in terminally ill patients due to the presence of severe conditions and the direct effects of treatment on their cognitive functions.

Although the QUALID scale has been widely adopted and translated into multiple languages, it has not been translated or officially used in Thailand. In that regard, the researcher is interested in studying and translating the QUALID scale into Thai in order to assess the effectiveness of treatment for terminally ill patients. Ultimately, the findings of this study will be conducive to the development of palliative care for terminally ill patients.

Objectiv of the Study

Primary Objectives

To translate the quality of life in late-stage dementia (QUALID) scale into Thai and evaluate its measurement properties in terms of validity and reliability.

Secondary Objectives

To study the patients' quality of life and the satisfaction of caregivers of terminally ill patients admitted to the medical wards at Golden Jubilee Medical Center, Mahidol University.

Scope of the Study

The instrument employed in this study was the quality of life in late-stage dementia (QUALID) scale. The QUALID scale was translated into Thai, and its validity and reliability were examined. The sample consisted of terminally ill patients who were admitted to the medical wards at Golden Jubilee Medical Center, Mahidol University. Data were collected from the caregivers of these patients. Since this study was a pilot study, a sample size of 30 respondents was determined.

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Expected Outcomes

1. Thai version of the quality of life in late-stage dementia (QUALID) scale that conforms to the standards.

2. Guidelines for future studies and development of the assessment of QOL of terminally ill patients.

Definition of Key Terms

1. *Measurement properties* means the psychometric properties of a research instrument, consisting of two aspects:

1.1 *Validity* refers to how well a research instrument measures what it is purported to measure, such as characteristics, behaviors, and content, and the extent to which it provides adequate coverage and accurate findings.

1.2 *Reliability* refers to the consistency of a research instrument, specifically the extent to which an instrument provides consistent outcomes if measurement is repeatedly performed.

2. *Quality of life (QOL)* means the functional effects of an illness in terms of physical, psychological, and social functioning, as perceived by the patient.

3. *Terminally ill patients* means patients who have been diagnosed with an incurable disease that cannot be adequately treated and is reasonably expected to result in death. Terminally ill patients are classified into two groups:

3.1 Patients with terminal or end-stage cancer

3.2 Patients with non-cancer chronic diseases such as stroke, late-stage dementia, chronic lung disease, chronic heart failure, and end-stage renal disease

4. *Caregiver* means a person responsible for providing direct care to the patient.

5. *Palliative care* means an approach to specialized medical care for patients with life-limiting illnesses. It focuses on maintaining patients' well-being and comfort without hastening or postponing their death, as well as improving the quality of life of patients and their families through the prevention and relief of suffering and the integration of psychological, social, and spiritual aspects of patient care.

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6. *Palliative performance scale (PPS)* means an instrument used to assess the functional performance of patients receiving palliative care. The PPS consists of 11 categories, which are measured in 10% decremental stages from 100% to 0% and are further divided into three stages:

6.1 Stable: PPS score of 70–100%

6.2 Transitional: PPS score of 40–60%

6.3 End-of-Life: PPS score of 0–30% (as detailed in the Appendix)

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CHAPTER II
RELATED WORK

In reviewing the literature and researches related to this study on the psychometric properties of the Thai version of the quality of life in late-stage dementia (QUALID) scale in terminally ill patients, the following concepts and research findings have been collated as supplementary materials to this study:

- Theoretical concepts of terminally ill patients
- Concepts and assessment of quality of life
- Concepts of instrument translation
- Psychometric properties of instruments

Theoretical Concepts of Terminally Ill Patients

Definition

Many definitions of terminally ill patients have been proposed, as follows:

Smith and Bonnette [8] defined terminally ill patients as those who have lost hope to be cured and are at the end stage of an incurable disease with gradual worsening of symptoms that eventually results in death.

William Sullivan [8] defined terminally ill patients as those who suffer from an illness that cannot be treated by any means of medical intervention except life-sustaining treatment such as spiritual care.

Sataporn Leelanantakit [9] referred to terminally ill patients as those who have been diagnosed with a progressive, chronic or late-stage disease that cannot be adequately treated, or those who have undergone all available therapeutic measures such that all treatment efforts have been utilized to the extent possible.

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It can be concluded that terminally ill patients are patients who suffer from a progressive disease that is non-responsive to treatment and can no longer be treated.

The only possible treatment for terminally ill patients is palliative care, which focuses on reducing pain and other symptoms, including physical, psychological, social, and spiritual aspects of care. In patients with terminal illness, their symptoms will gradually worsen and eventually result in death.

Understanding of Terminally Ill Patients

Regarding the fact that terminally ill patients suffer from an incurable disease and are subject to gradual worsening of symptoms that eventually leads to death, it is important for caregivers and family members to understand all changes experienced by these patients. Such understanding will enable caregivers and family members to provide appropriate care by means of palliative approach that will ultimately relieve the patients from pain and suffering. The changes and needs of terminally ill patients are as detailed below [10].

Physical Changes

Some of the most common symptoms experienced by terminally ill patients include pain, anorexia, cachexia, dyspnea, nausea, vomiting, weakness or fatigue, dry mouth, diarrhea or constipation, and skin problems such as ulcers and pruritus. Some patients may also experience several of these symptoms.

Psychological Changes

It is typical for patients facing death to experience stress, anxiety, and fear. Nonetheless, the majority of patients are not afraid of death itself. In fact, they generally fear of the processes leading to death, which may involve the suffering from excruciating pain and prolonged treatment. Likewise, patients may worry about their beloved ones who they are leaving behind. Near-death patients are most fearful of isolation, pain, and lack of self-control. They may express feelings such as anger, irritation, sadness, and depression—the extent to which depends on their physical, social, psychological, and spiritual conditions.

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According to Kubler-Ross [11], dying patients often go through five emotional stages as follows:

Stage 1 (Denial) is when patients recognize that they are nearing death and are in a state of shock and denial. They refuse to accept the reality and may believe that “this is not true” or manifest other behaviors, such as seeking treatment from various medical institutions. Caring for patients undergoing this stage requires acceptance of their reactions and provision of opportunities for them to fully express their feelings and concerns.

Stage 2 (Anger) is when patients become frustrated and may be thinking, “Why me?” They may also direct their anger to proximate individuals, saying certain things like “Why is the nurse so late?” In this stage, it is necessary to evaluate and accept patients’ behaviors, perceiving that these are the patients’ means of ventilating their feelings. Likewise, it is important to enable family members to understand these behaviors so as to make them feel comfortable and create a positive environment.

Stage 3 (Bargaining) is when patients attempt to bargain for an extended life in exchange for a reformed lifestyle, such as conducting or refraining from certain actions, engaging in a religious ceremony, and making an oath to a sacred item.

Stage 4 (Depression) is when patients despair at the recognition of their death, specifically the separation from their loved ones. They may become depressed or silent, experience insomnia, and spend most of their time mournful and sullen. Accordingly, caregivers should understand and respect the rights of patients by allowing them to do whatever they want while acting as a friend and lending a hand whenever needed. Caregivers should also help family members to understand the patients’ state of depression.

Stage 5 (Acceptance) is the final stage in which patients embrace the approaching and inevitable death, which is typically accompanied by feelings of calmness. They understand that death is the natural cycle of life and are ready to rest in peace. In this stage, patients want to spend time with their loved ones and have proximate individuals beside them. When communicating with patients undergoing this stage, visual and physical contact should be used. It is also important to keep in mind that, during this stage, patients are most afraid of being left alone.

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These psychological responses typically commence from Stage 1 to Stage 5 but are not necessarily found in all patients. Some patients may return to the previous stage depending on certain events and factors that affect them. Each patient

may undergo the five foregoing emotional stages at different time and to a varying degree. Some patients may be in a state of denial for the rest of their life, while some may not undergo all five stages, such as moving from Stage 2 directly to Stage 4. Likewise, patients with strong mental health may accept the reality faster than others. Indeed, these psychological responses are reversible; patients may have already accepted the reality upon diagnosis but return to the state of frustration or depression after the exacerbation of symptoms, such as losing the ability to walk. Hence, the Kubler-Ross theory is considerably comprehensive and flexible [12].

Various critiques have presented their viewpoints on the patients' emotional stages of dying proposed by Kubler-Ross [13], as follows:

1. The psychological responses of humans are uncertain and cannot be organized into a definite chronological sequence.

2. Humans may experience multiple emotions concurrently, such as denial and anger or anger and depression.

3. Bargaining should not constitute the five stages of dying since it is intrinsic for humans to consistently find alternatives for better life. It is indeed one of the methods of managing stress and impactful events experienced by individuals.

4. Other emotions such as fear and guilt are also commonly found in terminally ill patients, which hinder peace in the final stages of life. Likewise, patients manifesting a sense of humor may not always imply that they are in denial or being sarcastic. In fact, humor may be beneficial for patients in a sense that it reduces stress and provides them with a more optimistic view of life.

Robert Buckman proposed a theory on the psychological responses of terminally ill patients, which are classified into three stages as follows [13]:

1. In the initial stage of facing the threat, patients experience a variety of emotions depending on their characteristics, personal experience, and mechanisms of adaptation. These emotions include fear, anger, shock, stress, and anxiety, or the combination thereof. In this stage, psychological mechanisms may be employed to cope with the threat, such as denial, blame, and avoidance.

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2. In the chronic stage of being ill, the psychological responses in the initial stage are decreased in severity. Patients may become depressed and tedious as their final days are approaching. The people surrounding the patients may perceive

that the patients have an improved mental state and therefore being to distance themselves from the patients. Depression is common during this stage.

3. In the final stage of acceptance, patients accept the approaching death and exhibit a stable condition of emotions. Their decision making is appropriate to the reality.

Puchong Laorujisawad [13] postulated that there are three psychiatric disorders, namely 1) depression, 2) anxiety, and 3) delirium, which are highly prevalent in terminally ill patients.

1. Depression in terminally ill patients is attributable to various factors, including physical suffering or intractable pain, insomnia, prolonged inpatient treatment, lack of social support, disability, symptoms of diseases such certain types of cancer, and side effects of treatment such as chemotherapy drugs (vincristine, vinblastine, l-asparaginase, etc.), steroids, beta blockers, antiparkinson drugs, and amphotericin B.

2. Physical symptoms associated with anxiety include agitation, lack of focus, fatigue, and overactive nervous system such as tachycardia, hyperventilation, fainting, numbness, dysphagia, flatulence, and constipation. Some patients may also experience acute stress, such as dyspnea, dizziness, and irrational fear and worry.

3. Delirium is characterized by the acute onset of changes in cognition and awareness. It usually presents as a fluctuating level of consciousness and cognitive impairment and can manifest itself in a form of hyperactive and hypoactive delirium. Physical symptoms include disorientation, agitation, confusion, and day-night reversal.

Social Needs

It is undoubted that an illness takes an emotional toll on patients and affects their social aspect of life. Terminally ill patients are often discouraged and fear of being left alone and being a burden to others [14], especially to their families and society. Accordingly, it is normal for patients to seek social support from family, relatives, neighbors, and agencies or organizations. Once they feel loved, valued, and recognized by their social network, their mental and emotional health will improve, hence reducing their frustration. The provision of social support will further enable

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patients and families to ascertain the beauty of life despite the reality of having to leave or lose their loved ones.

Spiritual Needs

Hermann [15] conducted a qualitative study on the spiritual needs of 19 hospice patients who were at the final stages of life. According to the results, six spiritual needs of dying patients were identified, as follows:

1. Need for religion, such as the need to pray for healing, the need to read religious scriptures, the need to use religion for life guidance, and the need to participate in a religious ceremony
2. Need for companionship derived from family members, friends, children, and general individuals and need for support from those individuals
3. Need for self-control by means of making one's own decisions, as well as need for involvement in family activities
4. Need to fulfill one's duties, including business and estate affairs or other emotions experienced in the past
5. Need to experience nature, specifically the ability to step outdoors and indulge in the beauty of nature
6. Need for positive outlook, including positive conversations, cheerfulness, and encouragement

In addition, a qualitative study of Khwanta Baanthip et al. [16] conducted on 12 dying patients with AIDS found that the spiritual needs of these patients include:

1. Need for recovery from pain and suffering
2. Need for moral support and care from their loved ones, including individuals who understand and empathize with them and friends who can help them overcome loneliness
3. Need for warmth and comfort and need to bid farewell and entrust someone to fulfill their obligations
4. Need for care and assistance
5. Need for a peaceful death and good afterlife; patients want to make merits by themselves and want their family and relatives to consign merits to them, as

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well as arranging a funeral rite and scattering their cremated remains at sea under the belief that this will lead the soul to a good afterlife.

It is evident that the spiritual needs of terminally ill patients are related to their life philosophy and goals, or principles of high spiritual values that are important to life, and predominantly encompass the need to engage in religious activities. Terminally ill patients perceive that it is essential to secure attachment to their respective god so as to gain forgiveness, love, hope, and trust, while achieving meaning and ultimate goals in life or fulfilling the need to practice good deeds and refrain from evil acts [17]. The spiritual needs of terminally ill patients are concluded below.

1. Need for love and connectedness: Love is the fundamental need of all human beings. It is intrinsic for humans to establish relationships with the surrounding environment, which has an influence on personal development in various aspects, including cognition and feelings. Likewise, humans innately seek for love and develop attachment to family members, friends, personal items, environment, and nature. This is particularly true among inpatients who are isolated from their family, society, workplace, or familiar environment, and all the more so in terminally ill and dying patients who feel depressed, alone, and hopeless. Unquestionably, these patients need love and healthy relationships with family members, relatives, physicians, and nurses.

2. Need to search for meaning in life: Humans cannot live in solitude—we all want to live a meaningful life that provides values to our loved ones or benefits to ourselves and society. Indeed, generosity, love, and bonds of family members or friends are the main driving force of life, both in normal time and times of illness. Individuals with a strong spirit are often interested in religion or adhere to a philosophy of life, which is expressed in a form of behavior. These individuals live their life by adhering to personal values and expressing the need for involvement in religious activities. During the times of illness or life crisis, they will begin searching for meaning in life, specifically how to spend their remaining days in a meaningful manner. Self-realization of the meaning of life is crucial for dying patients; it enables them to ascertain who they are living for. Patients in this stage may also pose significant questions pertaining to suffering and death, such as “Why does this happen to me?” and “What will my life be like in the future?”

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3. Need for forgiveness: Terminally ill patients often contemplate their past life experiences, including events of happiness, fulfillment, sadness, and memorable mistakes, especially those in which they believe cannot be corrected or compensated due to a limited amount of time they have in life. Such contemplation will subsequently cause suffering and bitterness to patients. Moreover, terminally ill patients who reminisce about past events may sometimes experience confusion and conflicting thoughts. Patients in this stage are inclined to repent and confess their mistakes in effort to receive forgiveness. They may want to reconcile with and seek forgiveness from their past enemies. The solicitation of forgiveness in Buddhist patients or the confession of sins in Christian patients is crucial to the spirituality of terminally ill patients.

4. Need for religious practice: Religious practices are important for individuals in every culture. Having consciousness or self-awareness before death and recollecting good deeds or praying for inner piece will lead the soul to a good afterlife.

5. Need for hope: Hope is a need and positive goal that brings happiness to life. It is an optimistic state of mind that may manifest itself as a dream, inspiration, or motivation. Hope in terminally ill patients can be classified into two types as follows:

5.1 Concrete hope, such as hoping that their conditions will not deteriorate and their symptoms will improve and that they can take care of themselves, be with their children, and make merits or fulfill their mission.

5.2 Abstract or philosophical hope, such as hoping that they will go to heaven or be remembered by others and hoping to be with their family in the afterlife.

6. Need to be treated as an individual: Terminally ill patients often feel that they are physically, psychologically, and spiritually threatened. Treatment that employs modern tools may cause patients to feel as if they are under some power of which they cannot control or overcome. Likewise, they may feel threatened by the disease and death and therefore want to be treated as an individual with optimal quality of life throughout their remaining time.

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7. Need for immorality: Patients in this stage may want to be immortal. They may question about the afterlife, particularly in the aspect of immortality and happiness that corresponds to their religious belief.

8. Need to end life: Concerning the fact that life is an embodiment of separation and departure in which death is an inevitable part of life, patients want to die happy without suffering and pain. They want to engage in activities relating to merit and virtue. Only when their heart is filled with happiness can they leave the world in peace.

Essentially, the spiritual needs of terminally ill patients are the need to search for and fulfill their life goals, such as living their life by adhering to personal values and beliefs and expressing the need to be involved in religious activities in order to leave the world peacefully and happily.

It can be concluded that terminally ill patients undergo changes and express their needs in multiple aspects, including physical, psychological, social, and spiritual. All of these give rise to the concept of palliative care for terminally ill patients, which will be further described in the next section.

Concept of Palliative Care for Terminally Ill Patients

According to the World Health Organization [18], palliative care for terminally ill patients is one of the approaches to improving the quality of life of patients and their families through the prevention, assessment, and relief of suffering and other problems, including physical, psychological, social, and spiritual aspects.

The World Health Organization [1] defined palliative care as an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness. It encompasses the prevention and relief of suffering by means of alleviating symptoms or providing specialized care for patients with an incurable disease or those who are anticipated to deteriorate and die in the future. Palliative care entails a broad multidisciplinary approach that integrates the physical, psychological, social, and spiritual aspects of care. The primary goal of palliative care is to enhance the quality of life of patients and their families in such a

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manner that enables patients to die in peace and with dignity, while offering bereavement care for their families and relatives.

It can be inferred that palliative care for terminally ill patients is an interdisciplinary approach to specialized care for patients with life-threatening illnesses that aims to optimize the quality of life of patients and their families by means of preventing and alleviating physical stress and reducing other problems relating to psychological, social, and spiritual aspects.

Concepts and Assessment of Quality of Life

Quality of life has gained increased attention in clinical research over the past years. It has been incorporated into the goal of various healthcare organizations and can be applied to the assessment of treatment effectiveness and outcomes.

Definition

The World Health Organization Quality of Life (WHOQOL) Group asserted that quality of life (QOL) has been defined in many different ways depending on the context. In the perspective of policymakers such as government, QOL serves as security for citizens in respect of public services or social assistance, such as provision of public utilities, assistance in material need, and promotion of income equality and equal rights. Alternatively, in the view of economists, QOL refers to gross domestic product, inflation rate, consumer price index, and per capita income. Meanwhile, in the medical field, QOL means positive changes of treatment or rehabilitation of service users. Hence, the definitions of QOL vary to a great extent depending on the context in which it is used. Such variation in the concepts of QOL ultimately leads to differences in measurement and interpretation of results. The concepts of QOL that are widely accepted in clinical application can be classified as follows [5, 19, 20]:

1. Normal Life

The QOL under this concept refers to the state of being free from physical and psychological limitations and the ability to engage in daily activities and fulfill one's needs, which is accompanied by a relatively high life expectancy when compared to the population of the same age group or of normal health status. In

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other words, the QOL of a person can be determined from the differences in physical and psychological factors compared to the "standard" derived from the benchmark population. If any aspect of functional ability is lower than the "standard", such person is considered to have low QOL. It can be inferred that the QOL under this concept is primarily assessed from an individual's ability to perform daily activities and health status.

2. Social Utility

The QOL under this concept is defined as an individual's ability to maintain his/her social role and acceptance, such as the role of being a teacher, parent, employee, or employer. This concept emphasizes the impact of disease on occupational performance or the limitations to perform daily activities in relation to the social role following an illness or disability. The QOL under this concept is generally assessed from an individual's occupational status, income, and ability to maintain his/her social role when compared to the period before the onset of illness.

3. Utility

The definition of QOL under this concept can be divided into two perspectives, namely economic and psychological perspectives. In the economic viewpoint, QOL is defined as the health status of an individual compared to the reference criteria of the general population, and is measured using an index with a value between 0 and 1. A value of 0 denotes death, while a value of 1 indicates normal health. The QOL in the economic perspective only focuses on one perspective rather than a holistic perspective as evident in the concept of normal life. It reflects the cost-benefit dimension of treatment on the basis of economic foundation. When this concept is applied in the selection of treatment methods for patients with incurable diseases, such as cancer or disability, the cost-effectiveness of treatment is taken into account. The QOL under this perspective aims to maximize total benefits subject to costs of treatment, i.e. the "breakeven point". In case where there are multiple treatment options, the healthcare provider should opt for the most cost-benefit treatment [5].

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An alternative utility approach places importance on basic needs that affect the QOL (Figure 1). Accordingly, the QOL under this concept is assessed by means of objective evaluation based on the factors presented in Box A

(Figure 1). QOL is thus the achievement of an individual in relation to his/her needs, which can be determined from various factors such as the QOL questionnaire that has been specifically developed to examine QOL in Western countries. The limitation of this concept is accounted for by the fact that the questionnaire is limited to only one specific culture or context. Hence, the application of the questionnaire to assess the QOL of individuals in different cultures or societies may result in a lack of reliability and validity of the results. In that regard, it is necessary to ensure the validity and reliability of the questionnaire and its consistency with the culture in which the study will be conducted. Another limitation of this concept is the fact that the questionnaire is often constructed by a researcher, which is based on an "outsider or objective point of view". Since the factors affecting the QOL of the sample have been predetermined by the researcher, which may not be comprehensive or true to the sample, it is likely that the obtained results are inconsistent with the actual QOL of the sample. One of the examples that clearly substantiates this limitation is the QOL questionnaire of Western society in which the majority of items are related to sexual intercourse when in fact this factor may not have a significant influence on the QOL of the sample. Specifically, a previous study found that there were differences in the effects of sexual intercourse on the QOL between Eastern and Western culture [5].

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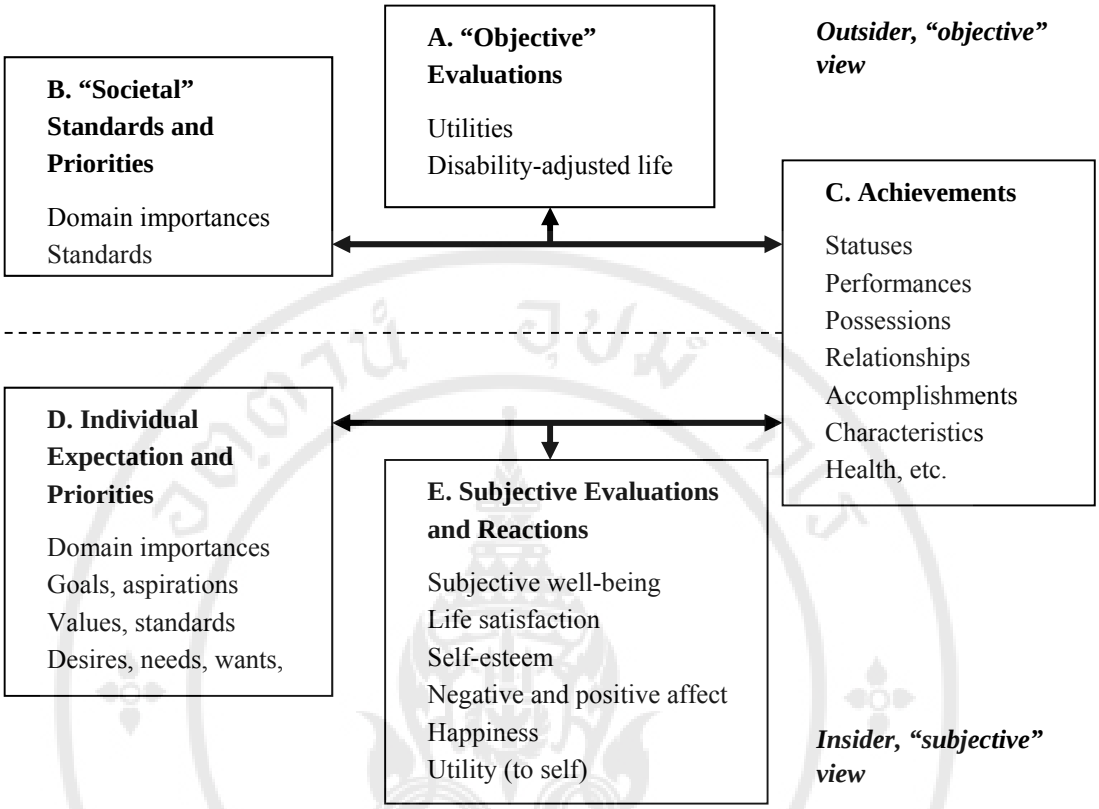

Figure 2.1 Concepts of quality of life: Utility approach: From: Dijkers M. Quality of life of individual with spinal cord injury: A review of conceptualization, measurement, and research findings. Journal of Rehabilitation Research & Development. 2005;42(3, Supplement 1): 87–110.

4. Life Satisfaction or Subjective Well-Being

This concept was developed under the belief that individuals have the rights and freedom to choose and prioritize what they want in life (Box D, Figure 2.1). The most important components of subjective well-being are the five levels of Maslow's hierarchy of needs as shown in Box A. These needs are then adjusted to correspond to each individual's culture and social values. Accordingly, each individual will have their own standard of comparison between their expectations (Box D) and achievements (Box C). The gap between individual expectation and achievement is considered to be the domain of subjective well-being (Box E). Hence, the QOL of individuals under this concept is the difference between individual

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expectation and achievement, whereby society and culture are the determinants of individual needs. QOL is thus subjected to each individual's prioritization of domains and satisfaction. With respect to the application of this concept, it is worth noting that the majority of researchers tend to focus only on the outcomes of individual achievements (Box C) while neglecting the importance of other domains (Box D). In actual fact, the domains in Box C and D are equally important for individuals' evaluation of their QOL. Another important aspect of implementing this concept is the self-evaluation of QOL through the use of cognitive judgments and emotional reactions. Simply put, the QOL of individuals is assessed from an "insider or subjective point of view". At present, this concept is regarded as the most appropriate approach to studying the QOL of individuals [19], and can be divided into four sub-concepts as follows:

a. Needs-Based Approach

Needs-based approach was developed from the concept of Thomas More who postulated that QOL is dependent on the satisfaction of certain basic needs, such as shelter and healthcare. This approach has been widely adopted in clinical research, specifically in the assessment of QOL in terms of health status or treatment effectiveness. The limitation of this approach is that it solely emphasizes the material or physical needs of individuals and does not take into consideration the spiritual and social aspects, under the belief that humans have similar basic needs according to Maslow's theory. In fact, individuals whose basic needs have been satisfied may still perceive their QOL to be low. With that respect, this approach does not provide a comprehensive measure of QOL due to negligence of psychological, spiritual, and social aspects. An example of this limitation is individuals of high social status who have satisfied all basic needs but still manifest a lack of happiness to such an extent that they need to seek for other alternatives, such as meditation and charitable work.

b. Want-Based Approach

This approach is based on the premise that individuals have different wants in life. The domains which affect the QOL of individuals are thus dependent on individual wants, whereby the QOL is a gap between individual expectation and achievement at certain period of life. Nonetheless, this approach is

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subjected to the condition that individuals' expectation must be realistic and based on their status in order to narrow the gap between their expectation and achievement, i.e. improve their QOL. For instance, when patients with complete tetraplegia are asked about their wants or goals of rehabilitation in a client-centered therapy session, their responses are often related to their desire to be able to walk again. These responses are considered as their "expectation". However, "realistically" speaking, it is unlikely that patients with complete tetraplegia will walk again—they will have to rely on wheelchairs for the rest of their life. Accordingly, to improve the QOL of patients, physical therapists should provide patients with knowledge regarding their condition in order to induce them to have a realistic expectation and accept their disability. Once the patients accept the reality and the importance of undergoing wheelchair training, they will perceive that their QOL has improved. One of the major concerns of this approach is that individuals have different expectations. Hence, it often raises the question of whether realistic expectation should be determined by the patient or the physical therapist. In that regard, the implementation of this approach requires both the patient and physical therapist to be flexible and accept the reality, which can be achieved through various methods such as adaptation and having optimistic personality.

c. Global Concept Approach

The shift from a reductionist approach to a holistic approach in clinical research subsequently gives rise to the change in the concept of QOL, as reflected by the emergence of the "global concept of quality of life" [21] developed by the World Health Organization. According to the World Health Organization, QOL is defined as:

"An individual's perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships, and their relationship to salient features of their environment."

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It is apparent that the World Health Organization places emphasis on a holistic approach and has developed the "global and dynamic concept" of QOL to encompass all domains of humanity, including physical, psychological,

social, and environmental aspects and personal beliefs. In addition, upon the World Health Organization's development of the framework on the classification of health components of functioning and disability, or the so-called "International Classification of Functioning, Disability and Health (ICF)", the said framework has been widely implemented in the assessment of QOL of patients. For instance, the framework postulated by Post and Noreau [22] (Figure 2.2) draws on the ICF framework to assess life satisfaction or QOL based on health components, including the effects of these components on QOL.

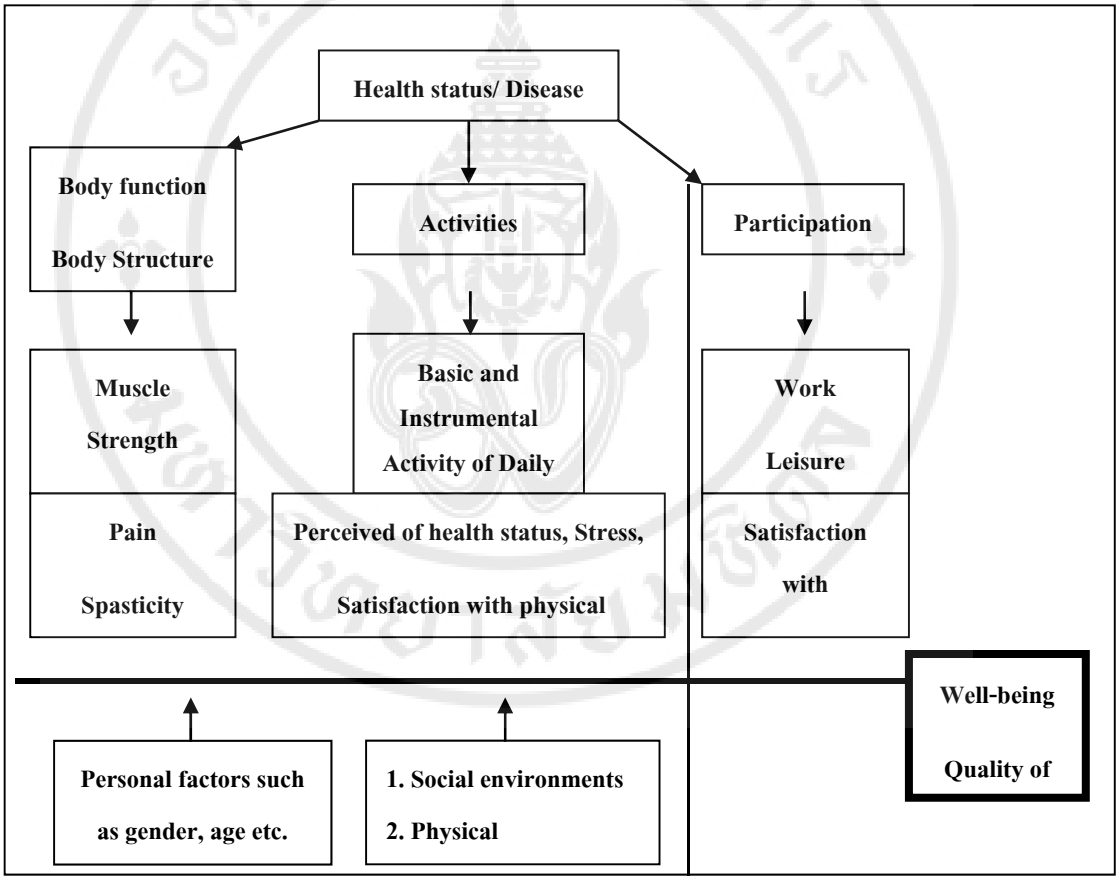

Figure 2.2 Comparison between QOL and ICF concepts: Adapted from: Post M & Noreau L. Quality of life after spinal cord injury. J Neurol Rehabil. 2005; 29(3):139–46.

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d. Metatheory Approach

This approach was conceptualized based on the concept that QOL comprises objective and subjective domains, each of which consists of

fundamental aspects. This specific framework on QOL is referred to as “metatheory”, owing to the fact that each domain or aspect draws on multiple theories in the belief that QOL cannot be expounded by only one theory [5].

5. Happiness/Affect

This concept attaches significance to the emotional state of individuals at a particular point in time. According to this concept, individuals place importance on the balance between positive feelings (happiness) and negative feelings (suffering and depression), whereby such balance is a temporary condition influenced by external and internal factors of each individual. Hence, the QOL under this concept is subjected to constant change and may vary on a daily basis, even if individuals are in the same situation or environment. In addition, this concept measures the QOL by evaluating individuals’ level of depression and emotional state. Specifically, individuals with a high level of depression are interpreted to have low QOL [19].

6. Natural Capacity

This concept focuses on the comparison between the physical and mental capacity of individuals before and after the onset of illness based on the assumption that QOL will deteriorate in the presence of illness. The QOL under this concept is thus assessed by taking into consideration the extent of deterioration in individual capacity and the degree to which such deterioration has an influence on individuals. This concept ultimately poses the question, “Is life worth living?” Accordingly, the QOL can be assessed by the patients themselves or from the perspective of caregivers and physicians who have a strong relationship with the patients or are aware of the changes in health conditions or impact of illness on the patients’ capacity [19].

Assessment of Quality of Life

It is widely accepted that QOL should be assessed in accordance with the concept of life satisfaction or well-being, which is a holistic approach that takes into account all factors affecting the QOL of individuals. The assessment of QOL can be classified into two types based on the data obtained from the study, as follows [20]:

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1. Qualitative Measurement

This type of measurement is suitable for studying the QOL of participants who have never participated in the study. It is conducted based on an insider perspective by interviewing the participants to obtain information concerning their thoughts and feelings without any guidance from the researcher. If the obtained results found that the domains of QOL differ from those obtained from a previous study, such results can be used to construct a new framework on QOL or serve as a basis for further development of QOL assessment.

2. Quantitative Measurement

Quantitative measurement is conducted based on the domains of QOL that have been predetermined by the researcher, through the use of questionnaire that corresponds to the framework. This type of measurement is appropriate for a study with a large sample size that aims to examine the effects of any particular factor or condition, such as illness, disability, and disaster, on the QOL. Quantitative measurement can be in a form of objective and subjective measurement. Objective measurement assesses the impact of disability based on the degree of physical impairment and the ability to perform activities, while subjective measurement assesses the impact of disability on social participation. Although previous studies found a clear relationship between the objective domains and the degree of physical impairment and ability to perform activities, researchers should bear in mind that objective domains are merely factors affecting the QOL, not indicators of the QOL. This is due to the fact that QOL must be derived from the perception of the sample at a particular point in time and is subjected to constant change, even if there are no changes in the degree of physical impairment or the ability to perform activities. It has been widely accepted that QOL is the outcome of domains in respect of physical impairment, ability to perform activities, and social participation, according to the ICF framework. Likewise, it is the outcome of the interaction between objective and affective domains that affect the overall QOL of the sample.

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Quality of Life Questionnaire

QOL questionnaire is a form of quantitative assessment that has been widely adopted in the field of research and can be divided into two groups [19]:

1. Health-Related Quality of Life (HRQOL) Questionnaire

HRQOL questionnaire is used to assess the impact of health conditions, such as illness and disability, on the domains of QOL selected by the researcher. In other words, it assesses the impact of illness on body structures and functions and activities. This type of questionnaire can be further divided into two sub-groups, as follows [20]:

1.1 Specific HRQOL Questionnaire

This type of questionnaire is constructed to examine a specific sample of patients who have the same health condition or are diagnosed with the same disease. It encompasses items pertaining to the symptoms, complications and effects of the disease, and is thus sensitive to detect changes in QOL after treatment. Nonetheless, it is worth noting that this type of questionnaire is designed for a specific sample. Hence, the obtained results may not cover other dimensions that affect QOL. Moreover, its scope of QOL assessment may be limited to the effects of treatment on physical functioning that are of the researcher's interest, hence overlooking other significant domains that may affect the overall QOL of patients. Another limitation of this type of questionnaire is that the obtained results are not applicable to other sample groups due to variation in the disease. Similarly, the use of this type of questionnaire in different cultures or languages may be susceptible to erroneous translation of the assessment results. Examples of this type of questionnaire include Asthma Quality of Life Questionnaire (AQLQ), Spinal Cord Injury Quality-of-Life Questionnaire (SCIQL-23), Rheumatoid Arthritis Quality of Life Questionnaire (RAQoL), and Stroke-Specific Quality of Life Scale (SSQL).

1.2 Generic HRQOL Questionnaire

Another approach to assessing the effects of disease or illness on QOL is generic HRQOL questionnaire, which employs a metatheory approach to measure a comprehensive array of domains that have an influence on QOL. The advantage of this type of questionnaire is that it can be used to evaluate QOL of patients with different types of diseases or disabilities. The primary

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goal of generic HRQOL questionnaire is to study the effects of disease or illness on certain aspects of health determined by the researcher. Some of the most commonly used generic HRQOL questionnaires include Medical Outcomes Study Short Form 36 (SF-36) and Nottingham Medical Outcome Questionnaire. This type of questionnaire can be used to evaluate a broader range of patients than specific HRQOL questionnaire.

2. Holistic Quality of Life Questionnaire

Holistic QOL questionnaire involves a comprehensive assessment of domains that have an influence on QOL, as predetermined by the researcher. These domains consist of physical and psychological functioning, ability to perform activities, social participation, economic status, physical environment, social environment, religious belief, and spirituality. Hence, this type of questionnaire provides a more holistic measurement of QOL than HRQOL questionnaire. One of the features of holistic QOL questionnaire is that it can be used to study the effects of changes in various domains on QOL without reference to the disease, illness, or clinical changes arising from treatment. Indeed, holistic QOL questionnaire has been continually and widely developed. Examples of such include Health Organization Quality of Life Questionnaire-100 (WHOQOL-100), World Health Organization Quality of Life Questionnaire-BREF (WHOQOL-BREF), Integrative Quality-of-Life Meta-Theory (IQL), Quality of Well Being Scale (QWB), European QoL Measure (EuroQoL), Life Satisfaction Index (LSI), Satisfaction with Life Scale (SWLS), and Comprehensive Quality of Life Inventory (ComQOL).

Quality of Life in Late-Stage Dementia (QUALID) Scale

It is considerably difficult to assess the QOL of patients with late-stage dementia owing to their limited ability to communicate and engage in activities pertaining to the improvement of QOL. The quality of life in late-stage dementia (QUALID) scale was thus developed by Myron F. Weiner et al. in 2000 to be used in the assessment of the management and outcomes of treatment that affect QOL of patients with late-stage dementia.

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The QUALID scale is based on a one-week window of direct observation of patients' behaviors or emotions performed by proxy informants such as trained

specialists or personnel in a medical institution. The QUALID scale is administered in an interview format (in accordance with the QUALID questionnaire) to an informant, which may be either a family member or professional caregiver who has spent at least 30 hours with the patient over the past seven days [7, 23].

The QUALID questionnaire consists of 11 items as described below, each of which is rated on a five-point scale.

1. Smiles
2. Appears sad
3. Cries
4. Has facial expression of discomfort
5. Appears physically uncomfortable
6. Verbalizations express discomfort
7. Is irritable or aggressive
8. Enjoys eating
9. Enjoys touching/being touched
10. Enjoys interacting with others
11. Appears calm and comfortable

The possible scores range from 11 to 55, with 11 representing the highest QOL.

According to a previous study, the QULAID scale was found to have a high level of internal consistency (Cronbach's $\alpha = 0.769$), test-test reliability (ICC = 0.807), and consistency across recorders (ICC = 0.826). Moreover, the QUALID score was found to have no correlation with the MMSE or PSMS score, but it was found to be significantly correlated with the NPI score ($R = 0.40$, $P = 0.01$) and the GDS score ($R = 0.36$, $P = 0.04$) [7].

In addition, the QUALID scale was found to be responsive to changes in the behaviors of patients and effects of treatment. These qualities make it appropriate to be used in determining the treatment guidelines for patients [23, 24].

The QUALID scale is widely accepted and adopted and has been translated into multiple foreign languages, such as Finnish, Spanish, Swedish, German, Dutch, Estonian, and Italian [24].

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Based on the foregoing information, it can be concluded that the QUALID scale is an instrument used in the assessment of QOL of patients with late-stage dementia. It has been studied and developed in several contexts, including in the aspect of cross-cultural adaptation. Many previous studies reported that the QUALID scale is a standardized instrument, hence its extensive use in clinical research.

Alternatively, the QUALID scale has also been used in palliative care for terminally ill patients with cognitive impairment. A previous study suggested that the QUALID scale is capable of assessing the QOL of patients in an efficient manner [25]. In that regard, the researcher is interested in applying a Thai version of QUALID scale in palliative care in Thailand. Concerning the fact that the use of any questionnaire entails thorough contemplation of the context of study and the validity and reliability of the questionnaire, the researcher finds it necessary to conduct a pilot study on the QUALID scale. This pilot study will enable the researcher to identify the appropriateness of the QUALID scale, as well as any potential problems or obstacles that may arise from its application. If the QUALID scale is found to be appropriate for use in the context of palliative care for terminally ill patients in Thailand, it will ultimately be conducive to future development and planning of palliative care.

Concepts of Instrument Translation

The quality of research instruments plays a significant role in the field of research, owing to the fact that a low-quality instrument may undermine the reliability of research findings, making them untrue to the sample population. Considering the complexity and time-consuming process in the development of research instruments, the majority of research instruments which have been developed in foreign countries or generally accepted as standard instruments have been translated into Thai to be used in research. The extensive use of translated instruments is accounted for by the acceptance of quality and standard of the original version of instruments. Notwithstanding the foregoing, researchers should employ appropriate translation techniques and place emphasis on language and cultural differences to ensure consistency of the translated instrument with the original version.

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The translation of a research instrument may cause the underlying structure of the instrument to change. Hence, the reliability and validity of the translated instrument may not be consistent with that of the original version, even if it has been correctly translated by a specialist. Concerning the fact that the sample population is often culture-specific, it is important to take into consideration the cultural equivalence and the quality of translation and translated instrument to maximize the reliability of research findings.

Instrument Translation Techniques

The purpose of instrument translation in cross-cultural research is to achieve cultural equivalence between two different languages. Since the translated instrument is not constructed based on theories but on the original version of the instrument that has been examined in terms of validity and reliability, the process of translation should be emphasized. Likewise, the instrument should be translated with a reliable procedure or technique. There are various techniques of instrument translation in clinical research, namely [26]:

1. Forward-only translation
2. Forward-only translation with testing
3. Back-translation
4. Back-translation with monolingual test
5. Back-translation with bilingual test
6. Back-translation with both monolingual and bilingual test

The technique of instrument translation that has been widely adopted in clinical research is back-translation, which is a technique used to assess the accuracy of translation. The procedure of back-translation technique is as follows:

Step 1: Forward translation, which involves translating the source language into the target language upon approval of the developer of the original instrument. In this step, the instrument may be translated by the researcher provided that he/she has adequate knowledge and understanding of both languages, or by a professional translator. A symmetrical approach should be adopted in the translation to achieve equivalence between two languages, i.e. source language and target language. The translator should contemplate the definition of the original term and use general

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and acceptable language for the broadest audience, ensuring that the translated instrument is consistent with the target culture. If the original version of the instrument is culture-specific and inappropriate to the target culture, cultural adaptation should be employed in the translation. In such case, the researcher should notify the instrument's developer of any modifications made to the instrument. In this step, the translator should be someone who is knowledgeable of the contents covered by the instrument and familiar with the target audience so as to ensure that appropriate language is used in the translation.

Step 2: Review of the translated version, which includes reviewing the accuracy and appropriateness of the language used in the translation; whereby the reviewer should not be the same person as the translator in the first step. In practice, the researcher may request his/her colleague to verify the accuracy of translation. Alternatively, in the case of a student's thesis, the thesis supervisor should be responsible for reviewing the accuracy and appropriateness of the translated version prior to the conduct of backward translation by a second translator.

Step 3: Backward translation, which involves translating the target language into the source language. In this step, the translator should be a bilingual person who is not the same person as the translator in the first step. In addition, the translator should not have prior knowledge of the original version of the instrument in order to minimize bias in the backward translation.

Step 4: Comparison of the original version and the back-translated version, which emphasizes linguistic and cultural equivalence. If any discrepancy is found, it should be thoroughly analyzed to identify which step contributes to such discrepancy. In such case, forward and backward translations should be iterated as many times as needed until a satisfactory version is reached. Moreover, this step can be performed by submitting the back-translated version to the instrument's developer for consideration. This approach allows the researcher to obtain feedback regarding content equivalence between the translated and original version. In case of discrepancies, the researcher should discuss with the developer to identify ways to adjust the translated version in such a manner that corresponds to the target culture. In practice, the researcher should examine any back-translated item with which its meaning deviates from the original version. Such problematic item should be corrected by the forward and backward

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translators until equivalence between both languages is obtained. If there is equivalence between the original and back-translated version, it can be inferred that both versions of the instrument carry the same intended meaning.

Step 5: Pre-testing the translated instrument on the sample population. This step is crucial as it does not only determine the appropriateness of the translated instrument but also the respondents' understanding of the items covered in the questionnaire. The results of pre-testing enable the researcher to ascertain whether or not the translated instrument is capable of measuring what it is purported to measure. In this step, the researcher may ask the respondents additional questions, such as "What do you think this item means?" and "Do you have any suggestions for this item?" The respondents' responses to these questions will confirm their understanding of each item and can be used to improve the comprehensiveness of the translated instrument.

Assessment of Instrument Quality

Prior to the actual application of the translated instrument, its quality and equivalence with the original version should be examined, which can be performed as follows [26]:

1. Comparison of the original version and the translated version by an expert, which includes consideration of contextual and content equivalence and provision of recommendations on language clarity and cultural appropriateness.

2. Comparison of the responses of bilingual and/or monolingual respondents between both versions of the instrument, wherein the scores obtained from both versions are statically analyzed by using item analysis or kappa statistic to assess item-to-item agreement.

3. Comparison of validity and reliability between the translated version and the original version. If the validity and reliability of the translated version are consistent with that of the original version, it can be inferred that there is equivalence between the two versions. Since the translated instrument may be regarded as a newly constructed instrument, the acceptable value of the alpha coefficient should be 0.7 or higher. In addition, if the original version of the instrument has been tested for

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construct validity by means of factor analysis, the translated version should be tested in the same manner.

Accordingly, it can be concluded that translation techniques play a significant role in the translation of instruments for cross-cultural research. Likewise, it is important for the researcher to select an experienced bilingual translator who is familiar with both cultures. Upon completion of each step of translation, the translated version should be examined in terms of its equivalence with the original version. Moreover, prior to using the translated instrument, its validity and reliability should be tested to ensure that the instrument can adequately measure what it is intended to measure and that the obtained results are reliable and can be generalized to the target population.

Psychometric Properties of Instruments

To maximize efficiency of a research instrument in collecting data to answer research questions, it is necessary to have a systematic procedure for constructing and developing the research instrument. In addition, the newly constructed instrument should be pre-tested, and the results thereof should be analyzed to identify its quality index according to the process described under “Assessment of Instrument Quality”.

Validity

1. Definition

Validity is defined as the degree to which a research instrument measures what it is designed to measure, and not something else instead.

Validity is the consistency or appropriateness of the outcomes in respect of content, criterion, and construct [27].

Validity measures the quality of a research instrument in forecasting future behaviors or correlation coefficients between outcomes and domains to be measured. Since each instrument serves different purposes, an instrument that is valid for a particular purpose does not necessarily have to be valid for all other purposes [28].

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To conclude, validity refers to the quality of a research instrument in measuring the attributes, behaviors, or contents it purports to measure in an accurate, comprehensive, and efficient manner and to the extent that conforms to the reality.

2. Nature of Validity

In testing the validity of a research instrument, the following points regarding the nature of validity should be taken into consideration [29]:

2.1 Validity is based on the interpretation of the outcomes obtained from the instrument and is thus not a property of the instrument itself.

2.2 Validity is presented as the degree to which differences discovered with the instrument reflect true differences.

2.3 Validity is a property specific to a particular purpose of study, hence no instrument is valid for all domains or purposes.

2.4 Validity is a unitary concept, requiring multiple sources of evidence to support the validity of the intended interpretation. These validity evidence may in a form of purpose, content, criterion, and construct.

3. Types of Validity

Validity can be categorized into three types as follows [30]:

3.1 Content validity is the degree to which a research instrument provides adequate coverage of content, knowledge, or experience to be measured, or the degree to which it fully represents knowledge or experience. There are two steps to establishing content validity evidence. First, variables are categorized to cover the concept or purpose by constructing a table of specifications. Second, the instrument is developed to cover the variables and intended purpose, which can be examined by: 1) evaluating the appropriateness of the definition and scope of content or experience to be measured, which is conducted by an expert in that field; 2) evaluating certain contents or behaviors that are consistent with all facets of a given construct; and 3) evaluating the degree to which the test items are consistent with each content domain to be measured.

3.2 Criterion-related validity is the degree of correspondence between the test and external referents, and can be categorized as follows:

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3.2.1 Concurrent validity refers to the extent to which an instrument correlates with other measures of the same construct that are

taken at the same time. It can be evaluated by calculating the correlation coefficient between the scores obtained from the instrument and those obtained from related measures at the same time. A correlation coefficient of 0.80 or higher denotes the concurrent validity of the instrument.

3.2.2 Predictive validity refers to the extent to which an instrument correlates with other measures of the same construct that are taken at some time in the future. It can be evaluated by calculating the correlation coefficient between the scores obtained from the instrument and those obtained from other validated measures at some point in the future.

3.3 Construct validity is the degree to which an instrument measures a construct as defined by a theory. It can be evaluated by determining how well the scores on the instrument are indicative of the theoretical construct, based on expert judgement, or by means of multitrait-multimethod matrix analysis or domain analysis.

Reliability

1. Definition

Reliability is the degree of to which an instrument gives the same repeated result under the same conditions [31].

The definition of reliability can be approached in three ways: 1) Reliability is analogous to stability, dependability, and predictability; 2) Reliability is the lack of distortion of an instrument; and 3) Reliability is the relative absence of errors of measurement in an instrument [32].

Reliability is the correlation coefficient between one set of scores and another set of scores on an equivalent instrument obtained independently from members of the same group [33].

It can be concluded that reliability is the ability of an instrument to yield the same, similar, stable, or consistent results when repeated over time.

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2. Reliability Estimation Methods

The reliability of an instrument can be determined using the following methods [31]:

2.1 Measure of stability is a test-retest method in which an instrument is tested on the same group of respondents at two different points in time. The obtained results are then used to compute the Pearson product-moment correlation coefficient, which may range from -1 to 1. Nonetheless, concerning the fact that the correlation coefficient is calculated from the original and new scores of the same group of respondents, its value will be between 0 and 1. In using this method, it is important to make sure that the variables to be measured are stable and that the test-retest is performed over an appropriate period of time. In other words, if the internal between the first and second test is too short, respondents might answer based on their memory of the first test. Alternatively, if the interval between the two tests is too long, extraneous variables such as maturation may interfere with the results.

2.2 Measure of equivalence or equivalent-form method is performed by testing two equivalent sets of an instrument on the same group of respondents at the same time. The scores on both sets of the instrument are used to compute the Pearson correlation efficient. Two sets of an instrument are considered equivalent or parallel if they measure the same construct and content and have similar means, variances, precision, and standard error. The reliability of an instrument can be determined by dividing the respondents into two groups of equal number. The first group is then asked to complete set A followed by set B, and vice versa for the second group. The correlation efficient obtained from this method will range from 0 to 1.

2.3 Measure of stability and equivalence or test-retest method with equivalent forms of an instrument is performed by testing two equivalent forms of an instrument on the same group of respondents at two different points in time. The scores obtained from both forms are then used to compute the Pearson correlation efficient.

2.4 Measure of internal consistency or internal consistency method is employed to estimate the reliability of an instrument through one administration of an instrument to the same group of respondents. The results are used to analyze the homogeneity of an instrument, specifically the extent to which the items on an instrument measure the same construct and produce consistent results. Common methods of testing for internal consistency are as follows:

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2.4.1 Split-half method involves dividing the test into two equivalent sets (e.g. by splitting the test based on odd and even items, randomly selecting the items, or creating matched item pairs based on the content to produce two sets of the test). These two sets are then administered to one group of respondents. The scores obtained from both sets are used to compute the Pearson correlation efficient in order to determine the split-half reliability. The full-length reliability of the test is then estimated based on the split-half values by using the Spearman-Brown Prophecy formula.

2.4.2 Cronbach's alpha method involves dividing the test into a number of items (k). The variance of individual scores and the variance of the total score can be used to estimate the internal consistency reliability of the test, which is presented as "Cronbach's alpha coefficient (α-coefficient)". Nonetheless, this method is only applicable when the test is unidimensional and the number of items or each domain in the set are equivalent. Notwithstanding the foregoing, this method is widely adopted since it involves only one test administration and is applicable to a variety of instruments, such as dichotomously scored test, weighted-score test, rating scale test, and subjective test.

2.4.3 Kuder-Richardson method was developed by Kuder and Richardson to address the limitations of the split-half method in which each method of split-half gives a different value of reliability. The Kuder-Richardson method can be used to estimate the reliability of a test that has a dichotomous scoring system (0,1). The formulas for this method are as follows:

2.4.3.1 The Kuder-Richardson Formula 20 (KR-20), which requires at least 20 items on the test wherein each item does not need to have the same level of difficulty.

2.4.3.2 The Kuder-Richardson Formula 21 (KR-21), which requires that each item on the test must have the same level of difficulty. Hence, this formula is less complicated but provides a lower limit for the computed coefficient than the KR-20 formula.

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CHAPTER III
METHODOLOGY

This research is a study of psychometric properties of the Thai version of quality of life in late-stage dementia (QUALID) scale in terminally ill patients. This chapter outlines the following:

1. Population of the study
2. Research instruments
3. Data collection
4. Data analysis

Population of the Study

Population

The target population for this study was defined to include terminally ill patients who were admitted to the medical wards at Golden Jubilee Medical Center, Mahidol University.

Sample

The sample employed in this study comprised terminally ill patients who were admitted to the medical wards at Golden Jubilee Medical Center, Mahidol University. Although data were collected from caregivers, the number of patients admitted to the medical institution was regarded as a primary factor that should be taken into consideration when calculating the sample size. Concerning the fact that terminally ill patients suffer from complex and severe conditions, they require a high level of care and attention from caregivers. Accordingly, each medical institution typically accepts a limited number of patients to ensure provision of extensive care, which subsequently gives rise to the limitation on the sample size. With such

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limitation in mind, the study was defined as a pilot study, whereby the appropriateness of the sample size was examined based on previous studies. According to Isaac and Michael (1995), the sample size for a pilot study was recommended to be 10–30 participants, which corresponded to the study of Hill (1998) who postulated that a sample size of 10–30 participants is sufficient for a pilot survey [34, 35]. The researcher therefore determined the sample size of this pilot study to be 30 respondents. The sample was selected by means of purposive sampling in accordance with the following criteria:

Inclusion Criteria

1. Terminally ill patients who were admitted to the medical wards at Golden Jubilee Medical Center, Mahidol University.

2. Caregivers who had spent at least 30 hours or three days with the patients over the past week.

3. Caregivers with reading and writing skills in Thai.

4. Volunteers who were willing to complete the questionnaire.

Withdrawal Criteria for Individual Participants

1. Caregivers who felt uncomfortable or uneasy while taking the questionnaire.

Research Instruments

1. General questionnaire, which includes questions such as patient's gender, age, relationship with the caregiver, duration of palliative care, and level of palliative performance scale (PPS).

2. Thai version of the quality of life in late-stage dementia (QUALID) scale, which was translated from the quality of life in late-stage dementia (QUALID) scale of Myron F. Weiner et al. (2000). The questionnaire consists of 11 items, which are related to the behaviors or emotions expressed by the patient. Each item is rated on a five-point scale. Scores are summed to range from 11 to 55, wherein lower scores reflect higher QOL.

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Translation of QUALID Scale

1. The researcher obtained approval from Myron F. Weiner for the translation of the quality of life in late-stage dementia (QUALID) scale into Thai.

2. The QUALID scale was translated using the back-translation technique, as detailed below.

a. The QUALID scale (original version) was translated into Thai and thereafter reviewed by an expert.

b. The translated QUALID scale with content equivalence to the original version was translated back into English by an expert (who is not the same person as the translator in the first step and had no prior knowledge of the original version).

c. The original version and the back-translated version were compared by the developer of the QUALID scale to examine appropriateness in language use.

3. The revised version of the translated QUALID scale was administered to the sample to examine its psychometric properties.

3. Caregiver satisfaction questionnaire on the use of the Thai version of QUALID scale, which consists of six items relating to the caregivers' opinions on the comprehensibility, clarity, and appropriateness of language used in the Thai version of QUALID scale. Each item is rated on a five-level scale as follows:

5 means extremely satisfied

4 means very satisfied

3 means moderately satisfied

2 means slightly satisfied

1 means least satisfied

The total score of the caregivers' satisfaction towards the use of the Thai version of QUALID scale was computed based on the sum of the scores obtained from six items on the questionnaire. Individual item scores and total scores were converted into a mean score to range from 1.00 to 5.00, each of which is defined as follows:

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Mean score of 1.00–1.99 means low level of satisfaction.

Mean score of 2.00–2.99 means moderate level of satisfaction.

Mean score of 3.00–3.99 means high level of satisfaction.

Mean score of 4.00–5.00 means highest level of satisfaction.

4. Caregiver satisfaction questionnaire on palliative care, which consists of nine items, each of which is rated on a five-level scale as follows:

4 means extremely satisfied

3 means very satisfied

2 means somewhat satisfied

1 means least satisfied

0 means dissatisfied

The total score of the caregivers' satisfaction towards palliative care was computed based on the sum of the scores obtained from nine items on the questionnaire. Individual item scores and total scores were converted into a mean score to range from 0.00 to 4.00, each of which is defined as follows:

Mean score of 0.00–0.99 means lowest level of satisfaction.

Mean score of 1.00–1.99 means low level of satisfaction.

Mean score of 2.00–2.99 means high level of satisfaction.

Mean score of 3.00–4.00 means highest level of satisfaction.

The caregiver satisfaction questionnaire on the use of the Thai version of QUALID scale and the caregiver satisfaction questionnaire on palliative care were constructed and developed according to the following procedures:

1. The researcher examined related documents, textbooks, and literature to be used as a guideline for the construction of questionnaires.

2. A draft version of the questionnaires was constructed to encompass all domains as defined in the study.

3. The questionnaires were proposed to the thesis advisor for consideration of the appropriateness of the questionnaire items with respect to the domains to be measured. Opinions of the thesis advisor were used to improve the questionnaires for higher clarity and pertinence, as well as to ensure that appropriate methods of measurement are adopted. The revised questionnaires were then used in the process of data collection.

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Data Collection

1. The study was proposed to the Human Research Ethics Committee of Mahidol University to obtain approval prior to commencement of the study.

2. Upon approval of the Human Research Ethics Committee, the researcher contacted Golden Jubilee Medical Center, Mahidol University to request for approval to collect data from the sample; whereby data were collected from February to September 2018.

3. The following questionnaires in Thai version were administered to the sample:

3.1 General questionnaire, consisting of four items *(conducted at baseline)*

3.2 Thai version of QUALID scale, consisting of 11 items *(conducted at baseline and two weeks thereafter)*

3.3 Caregiver satisfaction questionnaire on the use of the Thai version of QUALID scale, consisting of six items *(conducted at baseline)*

3.4 Caregiver satisfaction questionnaire on palliative care, consisting of nine items *(conducted upon discharge planning)*

4. The obtained data were used in the subsequent process, i.e. statistical analysis.

Data Analysis

Data were statistically analyzed with SPSS.

1. Analysis of Psychometric Properties

The reliability of instruments was analyzed using the internal consistency method and alpha coefficient.

2. Descriptive Statistical Analysis

2.1 Perform the frequency and percentage distribution of data, specifically patient's gender, age, level of palliative performance scale (PPS), relationship with the caregiver, and duration of palliative care.

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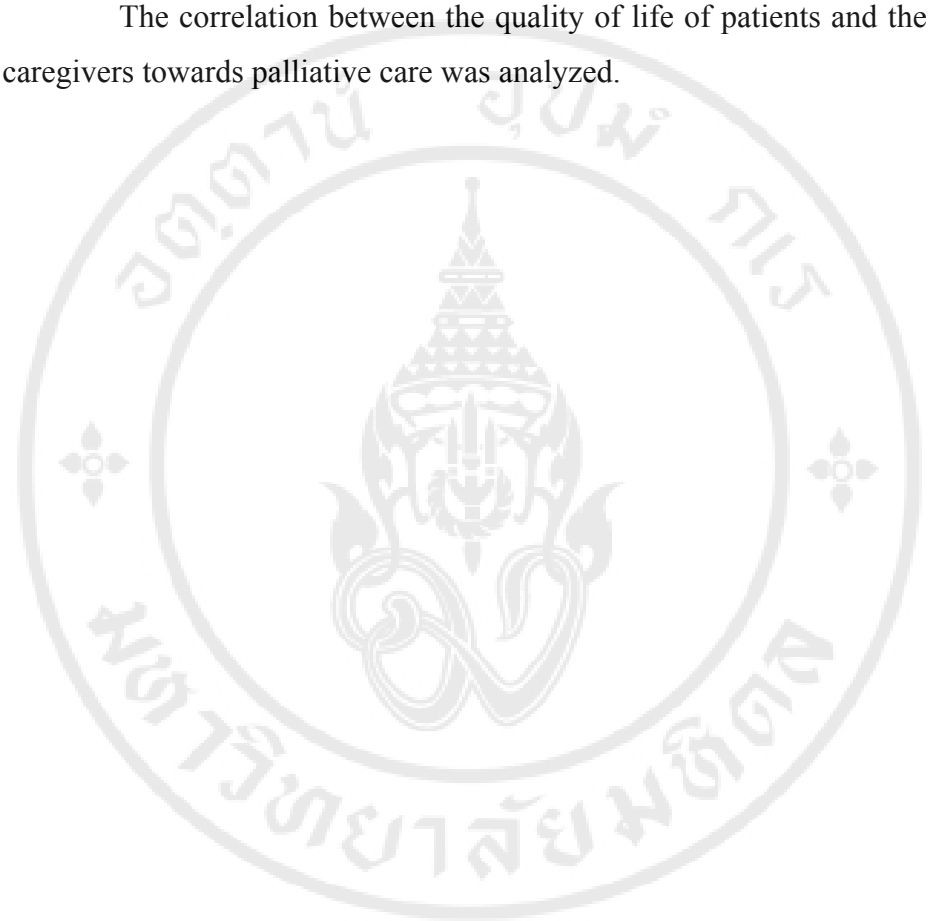
2.2 Determine the mean, median, mode, and range of the quality of life of terminally ill patients at Golden Jubilee Medical Center, Mahidol University.

2.3 Determine the mean ($\bar{x}$) and standard deviation (S.D.) of the satisfaction of caregivers towards the use of the Thai version of QUALID scale and palliative care.

3. Correlation Analysis

The correlation between the quality of life of patients and the satisfaction of caregivers towards palliative care was analyzed.



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CHAPTER IV
RESULTS

This research is a case study on the translation of the quality of life in late-stage dementia (QUALID) scale into Thai, which aims at examining the psychometric properties of the Thai version of QUALID scale in terms of validity and reliability.

The results of data analysis are presented as follows:

Part 1 Analysis of the baseline characteristics of the sample

Part 2 Analysis of the validity of the Thai version of QUALID scale

Part 3 Analysis of the reliability of the Thai version of QUALID scale

Part 4 Analysis of the caregivers' satisfaction towards the use of the Thai version of QUALID scale

Part 5 Analysis of the quality of life of the sample

Part 6 Analysis of the caregivers' satisfaction towards palliative care

Part 7 Analysis of the correlation between patients' quality of life and caregivers' satisfaction towards palliative care

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Part 1 Analysis of the baseline characteristics of the sample categorized by the patient's gender, age, level of palliative performance scale (PPS), relationship with the caregiver, and duration of palliative care

Table 4.1 Frequency and percentage of the sample by baseline characteristics

	Variable	Frequency (n=30)	Percentage
Gender	Male	11	36.7
	Female	19	63.3
Age	Below 60 years	3	10
	60–69 years	4	13.3
	70–79 years	6	20
	Above 80 years	17	56.7
PPS Level	0%–30%	26	86.7
	40%–60%	4	13.3
	70%–100%	-	-
Patient's Relationship with the Caregiver	Husband–wife	4	13.3
	Father–mother	-	-
	Son–daughter	17	56.7
	Relatives	3	10
	Paid caregiver	6	20
Duration of care	Less than 1–3 months	11	36.7
	4–6 months	4	13.3
	More than 6 months	15	50

According to Table 4.1, the majority of the sample were female (63.3%) and aged 80 years and above (56.7%). In addition, 86.7% of the sample had the PPS level of 0%–30%; 56.7% were cared for by their son or daughter who acted as a caregiver; and 50% spent more than six months in palliative care.

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Part 2 Analysis of the validity of the Thai version of QUALID scale

The content validity of the Thai version of QUALID scale was examined according to the following procedures:

1) Translate the original version of QUALID scale into Thai to be reviewed by an expert.

2) Translate the Thai version of QUALID scale back into English by an expert (who is not the same person as the translator in the first step and had no prior knowledge of the original version of QUALID scale).

3) Compare the original version with the back-translated version by submitting the latter to the developer of QUALID scale to be examined for language appropriateness and content equivalence. Details of the back-translated version submitted to the developer for consideration are as follows:

Quality of Life Questionnaire for Cognitively Impaired Patients in Palliative Care

Instructions: The informant should have provided care for the patient at least 3 days per week. This questionnaire will be based on behavioral observations from the past week only.

1. Smiling
    - 1.1 Smile by oneself more than or equal to 1 time/day
    - 1.2 Smile by oneself less than 1 time/day
    - 1.3 Smile only when stimulated at least 1 time/day
    - 1.4 Smile only when stimulated less than 1 time/day
    - 1.5 Rarely or not at all
2. Sad impression
    - 2.1 Rarely or not at all
    - 2.2 Only when stimulated, less than 1 time/day
    - 2.3 Only when stimulated, at least 1 time/day
    - 2.4 No clear causes, less than 1 time/day
    - 2.5 No clear causes, more than or equal to 1 time/day
3. Crying
    - 3.1 Rarely or not at all
    - 3.2 Only when stimulated, less than 1 time/day

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3.3 Only when stimulated, at least 1 time/day

3.4 No clear causes, less than 1 time/day

3.5 No clear causes, more than or equal to 1 time/day

4. Uncomfortable or painful facial expression, such as wry or frowning face

4.1 Rarely or not at all

4.2 Less than 1 time/day

4.3 At least 1 time/day

4.4 Almost or throughout half of the day

4.5 Almost or throughout the day

5. Physical discomfort, such as wriggling or frequently changing sleep positions

5.1 Rarely or not at all

5.2 Less than 1 time/day

5.3 At least 1 time/day

5.4 Almost or throughout half of the day

5.5 Almost or throughout the day

6. Make a sound that indicates illness, such as moaning or screaming

6.1 Rarely or not at all

6.2 Only when stimulated, less than 1 time/day

6.3 Only when stimulated, at least 1 time/day

6.4 No clear causes, less than 1 time/day

6.5 No clear causes, more than or equal to 1 time/day

7. Signs of irritation or aggression, such as angry, pushing, or attempting to do harm

7.1 Rarely or not at all

7.2 Only when stimulated, less than 1 time/day

7.3 Only when stimulated, at least 1 time/day

7.4 No clear causes, less than 1 time/day

7.5 No clear causes, more than or equal to 1 time/day

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8. Enjoy eating

8.1 Almost during every meal and snack time

8.2 2 times/day

8.3 At least 1 time/day

8.4 Less than 1 time/day

8.5 Rarely or not at all

9. Feel happy when in physical contact

9.1 Almost all the time—often initiate physical contact

9.2 More than half of the time—sometimes initiate physical contact

9.3 Half of the time—do not initiate nor resist physical contact

9.4 Less than half of the time—often resist physical contact

9.5 Rarely or not at all—always resist physical contact

10. Feel happy when being with other people

10.1 Almost all the time—often initiate the interaction

10.2 More than half of the time—sometimes initiate the interaction

10.3 Half of the time—do not initiate nor resist the interaction

10.4 Less than half of the time—often resist the interaction

10.5 Rarely or not at all—always resist the interaction

11. Appear calm and comfortable

11.1 Almost throughout the day

11.2 More than half of the day

11.3 Half of the day

11.4 Less than half of the day

11.5 Rarely or not at all

Total score _____ points (Total score will be in the range of 11–55: the lower the score, the higher the quality of life)

Upon submission of the Thai version of QUALID scale to Myron F. Weiner—the developer of the instrument—for examination, it was found that the Thai version of QUALID scale had appropriate language use and was able to convey the meanings and contents accurately in accordance with the original version. Accordingly, the Thai version of QUALID scale was deemed to have content

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equivalence with the original version and was thus appropriate for use in data collection.

Part 3 Analysis of the reliability of the Thai version of QUALID scale

Table 4.2 Reliability of the Thai version of QUALID scale in terms of Cronbach's alpha coefficient

Item No.	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
1	24.6667	32.782	.362	.586
2	24.3667	34.378	.239	.619
3	25.3667	42.102	-.110**	.669
4	24.1000	36.231	.213	.620
5	24.0333	33.275	.341	.591
6	23.8000	30.028	.547	.536
7	25.5667	38.392	.266	.610
8	25.4333	38.737	.174**	.622
9	23.8667	35.568	.495	.576
10	23.7000	34.769	.594	.562
11	23.1000	37.472	.173**	.626

**Items which have the corrected item-total correlation of less than .2, i.e. failing the criteria.

The level of reliability was determined from Cronbach's alpha coefficient based on the concept of Fisher and Corcoran in which the reliability coefficient (r) is rated on a four-level scale [36] as follows:

r value of 0.0–0.20 means very low level of reliability

r value of 0.21–0.40 means slightly low level of reliability

r value of 0.41–0.70 means moderate level of reliability

r value of 0.71–1.00 means high level of reliability

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According to Table 4.2, the Thai version of QUALID scale has the Cronbach's alpha coefficient of 0.627, i.e. a moderate level of reliability. Hence, it is acceptable to be used in a pilot study.

Upon consideration of individual items on the Thai version of QUALID scale, a total of three items (Item No. 3, 8, and 11) were found to have a corrected item-total correlation of negative value or less than 0.2. When these items were excluded from the analysis, the Cronbach's alpha coefficient of the Thai version of QUALID scale was found to increase to a small extent ($\alpha \approx 0.66$), while the reliability remained at the same, moderate level.

Part 4 Analysis of the caregivers' satisfaction towards the use of the Thai version of QUALID scale

Table 4.3 Mean, standard deviation, and level of satisfaction of the caregivers towards the use of the Thai version of QUALID scale

Satisfaction Towards the Use of the Thai Version of QUALID Scale	Satisfaction Level (n = 30)		
	Mean ($\bar{x}$)	S.D.	Level
1. Appropriateness of the number of items	3.93	.785	High
2. Appropriateness of the time spent on the QUALID scale	4.13	.681	Highest
3. Comprehensibility and clarity of language used	3.63	.890	High
4. Items' coverage of symptoms of the patient under your care	3.47	.937	High
5. Benefits of the QUALID scale on the treatment of patients.	3.93	.828	High
6. Overall satisfaction towards the QUALID scale	3.93	.828	High

According to Table 4.3, the caregivers' satisfaction towards the use of the Thai version of QUALID scale was at a high level ($\bar{x} = 3.93$).

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Upon consideration of individual items in descending order of satisfaction level, it was evident that: 1) The caregivers' satisfaction towards the appropriateness

of the time spent on the QUALID scale was at the highest level ($\bar{x}$ = 4.13); 2) The caregivers' satisfaction towards the appropriateness of the number of items and the benefits of QUALID scale on the treatment of patients was at a high level ($\bar{x}$ = 3.93); 3) The caregivers' satisfaction towards the comprehensibility and clarity of language used was at a high level ($\bar{x}$ = 3.63); and 4) The caregivers' satisfaction towards the items' coverage of the symptoms of patients was at a high level ($\bar{x}$ = 3.47).

Part 5 Analysis of the quality of life of the sample

Table 4.4 Frequency and percentage of QOL scores obtained from the Thai version of QUALID scale arranged in ascending order

QOL Score	Frequency	Percentage
20.00	1	3.3
24.00	3	10.0
25.00	1	3.3
26.00	3	10.0
27.00	1	3.3
28.00	2	6.7
29.00	1	3.3
30.00	3	10.0
31.00	5	16.7
32.00	2	6.7
35.00	2	6.7
36.00	1	3.3
37.00	3	10.0
38.00	1	3.3
39.00	1	3.3
Total	30	100.0

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According to Table 4.4, the lowest QOL score of the sample was 20 and the highest was 39 (the scores were in a range of 11–55), wherein lower scores reflect higher quality of life. Moreover, it was found that the majority of the sample (16.7%) had a QOL score of 31.

Table 4.5 Mean, median, mode, and range of QOL scores obtained from the Thai version of QUALID scale

Mean	30.33
Median	30.50
Mode	31.00
Range	19.00

According to Table 4.5, the QOL scores across the sample had a mean of 30.33, a median of 30.50, a mode of 31 (16.7%), and a range of 19 as illustrated in the graph below.

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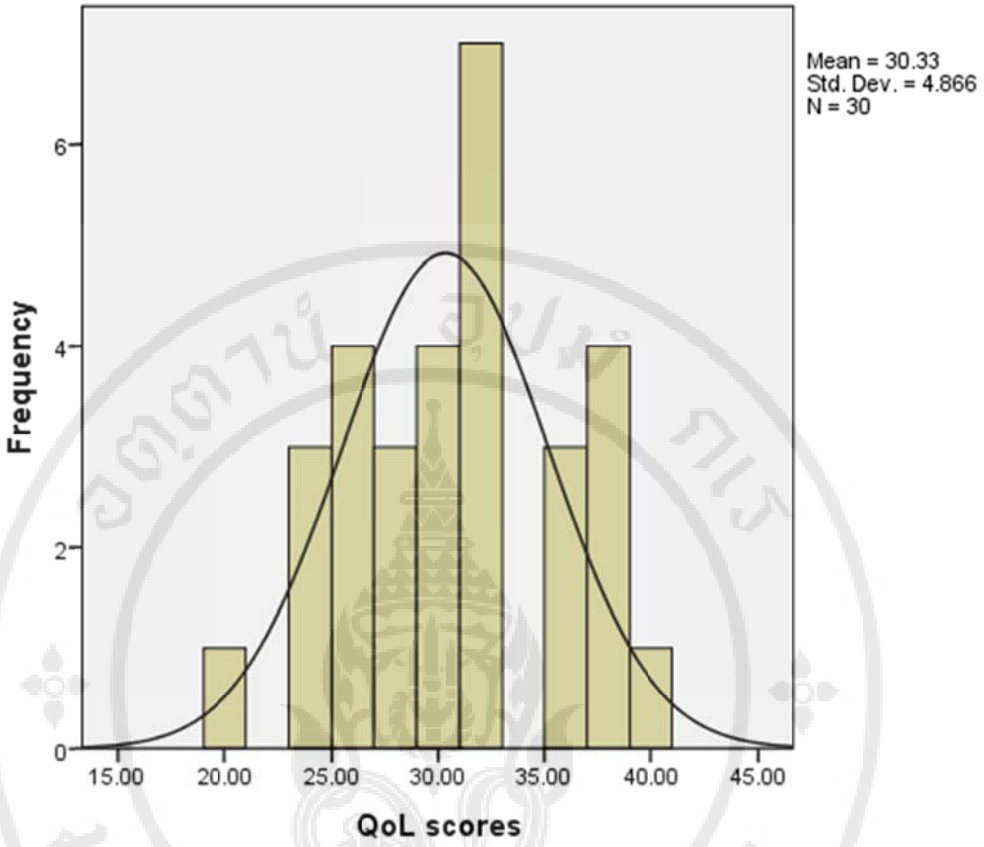

Figure 4.1 QOL scores of the sample

Part 6 Analysis of the caregivers' satisfaction towards palliative care

Table 4.6 Mean, standard deviation, and level of satisfaction of the caregivers towards palliative care

Satisfaction Towards Palliative Care	Satisfaction Level (n = 30)		
	Mean ($\bar{x}$)	S.D.	Level
1. You were informed by the healthcare team of the treatment goals and plans.	3.33	.606	Highest
2. You were continuously informed of the changes undergone by the patient.	3.17	.791	Highest
3. You are satisfied with the hygienic-sanitary conditions of the patient.	3.10	.759	Highest

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Table 4.6 Mean, standard deviation, and level of satisfaction of the caregivers towards palliative care (cont.)

Satisfaction Towards Palliative Care	Satisfaction Level (n = 30)		
	Mean ($\bar{x}$)	S.D.	Level
4. You perceive that the patient enjoys his/her food.	2.70	.988	High
5. You perceive that the patient gets adequate sleep.	3.37	.615	Highest
6. You are satisfied that the patient is not suffering from pain.	3.37	.718	Highest
7. You received care and moral support from the healthcare team.	3.03	1.098	Highest
8. You have knowledge and confidence in caring for the patient when he/she returns home.	3.17	.950	Highest
9. In overall, you are satisfied with the care provided by the healthcare team.	3.37	.669	Highest

According to Table 4.6, the caregivers' satisfaction towards palliative care was at the highest level ($\bar{x}$ = 3.37).

Upon consideration of the top three items with highest satisfaction level, ranked in descending order, it was evident that the caregivers' satisfaction towards patients' sleep adequacy and non-occurrence of suffering was at the highest level ($\bar{x}$ = 3.37); and their satisfaction towards information received from the healthcare team with respect to treatment goals and plans was at the highest level ($\bar{x}$ = 3.33), respectively.

Part 7 Analysis of the correlation between the patients' quality of life and the caregivers' satisfaction towards palliative care

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The researcher postulated that the provision of care in accordance with the treatment goals (e.g. improving patients' quality of life, relieving patients from pain and suffering, and keeping patients comfortable in their final stage of life) and the

caregivers' satisfaction towards the level of care provided by the healthcare team would reflect the efficiency of the treatment guideline.

Based on the foregoing concept, the Thai version of QUALID scale and the caregiver satisfaction questionnaire on palliative care—both of which had the same measurement structure and items relating to the goals of palliative care—were employed in the analysis. The following items which are equivalent between the two questionnaires were selected:

Items Obtained from the Thai Version of QUALID Scale

- The patient appears calm and comfortable.

Items Obtained from the Caregiver Satisfaction Questionnaire on Palliative Care

- You are satisfied with the hygienic-sanitary conditions of the patient.
- You perceive that the patient enjoys his/her food.
- You perceive that the patient gets adequate sleep.
- You are satisfied that the patient is not suffering from pain.

The observed scores were analyzed to identify the correlation between the patients' quality of life and the caregivers' satisfaction towards palliative care, of which the results are presented in the following table.

Table 4.7 illustrates the correlation between the patients' quality of life in the aspect of calmness and comfort and the caregivers' satisfaction towards palliative care in the aspect of hygienic-sanitary conditions of patients.

	Caregivers' Satisfaction Towards Palliative Care in the Aspect of Hygienic-Sanitary Conditions of Patients	
Patients' Quality of Life in the Aspect of Calmness and Comfort	Pearson Correlation	.621**
	Sig. (2-tailed)	< .00

**Correlation is significant at the .001 level (2-tailed).

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According to Table 4.7, when considering the correlation between the patients' quality of life and the caregivers' satisfaction towards palliative care with Pearson correlation, it was evident that the patients' quality of life in the aspect of calmness and comfort was positively correlated with the caregivers' satisfaction towards palliative care in the aspect of hygienic-sanitary conditions of patients (r = .621), at a significance level of < .001.

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CHAPTER V
CONCLUSION, DISCUSSION AND RECOMMENDATIONS

This "Study of Psychometric Properties of the Thai Version of Quality of Life in Late-Stage Dementia (QUALID) Scale in Terminally Ill Patients: Pilot Study in a Medical Setting" had the primary objectives to translate the quality of life in late-stage dementia (QUALID) scale into Thai and examine its psychometric properties in terms of validity and reliability.

The quality of life in late-stage dementia (QUALID) scale was translated into Thai upon approval of Myron F. Weiner, the developer of the instrument. The translated version was submitted to the developer to examine its language appropriateness and content equivalence. Once the translated version had been approved by the developer, it was administered to the sample for data collection.

Survey research was employed as a research methodology wherein questionnaires were used in collecting data. The questionnaires were divided into four parts as follows:

Part 1: General questionnaire, consisting of items relating to the baseline characteristics of the sample

Part 2: Thai version of the quality of life in late-stage dementia (QUALID) scale, consisting of 11 items rated on a five-level scale

Part 3: Caregiver satisfaction questionnaire on the use of the Thai version of QUALID scale, consisting of five items rated on five-level scale

Part 4: Caregiver satisfaction questionnaire on palliative care, consisting of nine items rated on a five-level scale

Data were collected from 30 terminally ill patients who were admitted to the medical wards at Golden Jubilee Medical Center, Mahidol University. The obtained data were subsequently subjected to statistical analysis.

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Conclusion

1. The majority of the sample were female (63.3%) and aged 80 years and above (56.7%). In addition, 86.7% of the sample had the PPS level of 0%–30%; 56.7% were cared for by their son or daughter who acted as a caregiver; and 50% spent more than six months in palliative care.

2. The Thai version of QUALID scale was reviewed by an expert who is the developer of the instrument. Hence, it was deemed to have content equivalence.

3. The Thai version of QUALID scale, which consists of 11 items, had the Cronbach's alpha coefficient of 0.627, i.e. a moderate level of reliability.

4. In overall, the caregivers' satisfaction towards the use of the Thai version of QUALID scale was at a high level ($\bar{x}$ = 3.93). Upon consideration of individual items, it was found that their satisfaction towards the appropriateness of the time spent on the questionnaire was at the highest level ($\bar{x}$ = 4.13).

5. The lowest QOL score of the sample was 20 and the highest was 39 (wherein lower QOL scores reflect higher QOL). The range of the total QOL score was 19 and the mean was 30.33. Hence, the sample had a moderate level of QOL.

6. In overall, the caregivers' satisfaction towards palliative care was at the highest level ($\bar{x}$ = 3.37). Upon consideration of individual items, it was found that their satisfaction towards patients' sleep adequacy and non-occurrence of suffering was at the highest level ($\bar{x}$ = 3.37).

7. The patients' quality of life in the aspect of calmness and comfort was positively correlated with the caregivers' satisfaction towards palliative care in the aspect of hygienic-sanitary conditions of patients (r = .621).

Discussion

The results of the study of psychometric properties of the Thai version of quality of life in late-stage dementia (QUALID) scale in terminally ill patients will be discussed under two main topics as follows:

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1. Psychometric properties of the Thai version of quality of life in late-stage dementia (QUALID) scale

The Thai version of QUALID scale was examined for content equivalence and reliability as follows:

1.1 In the aspect of content equivalence, the QUALID scale was translated using the back-translation technique. The Thai version of QUALID scale was reviewed by two language specialists and a health professional with expertise in the use of the instrument. In addition, the back-translated version was re-examined by the developer of the instrument for language appropriateness, content equivalence, conformity with applicable standards.

1.2 The reliability of the Thai version of QUALID scale was assessed using the internal consistency method and Cronbach's alpha coefficient. According to the results, the Thai version of QUALID scale has the Cronbach's alpha coefficient of 0.627, which implies that it has a moderate level of reliability.

The Thai version of QUALID scale was compared with the original version to determine equivalence between them. The results are presented in the table below.

Table 5.1 Descriptive statistics of the original and Thai version of QUALID scale

	QUALID (original)	**QUALID (Thai version)**
N	42	30
Mean ± S.D.	22.76 ± 7.40	30.33 ± 4.86
Range	12 - 45	20 - 39
Cronbach's α	0.769	0.627

According to Table 5.1, the Cronbach's alpha coefficient of the Thai version of QUALID scale is slightly lower than that of the original version. Such difference in reliability between the two versions could be accounted for by the statistical factors, as described below.

- The sample size is smaller.
- The homogeneity of the sample results in a smaller range of scores.

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These statistical factors directly contribute to lower reliability, which is consistent with the concept of F.N. Kerlinger who concluded that there are three primary factors affecting the reliability of an instrument [36], as detailed below.

1. Factors relating to inconsistent events, which often occur when more than one measure is taken or exchangeable questionnaires are used, including the difficulty of questionnaire items, have an influence on reliability.

2. Factors relating to questionnaire items, specifically the test length which is found to be positively correlated with reliability, i.e. the longer the test the higher the reliability.

3. Statistical factors such as the range of the sample variance also influence the reliability of the test. In other words, if there is high variability in the characteristics of the sample, the range of test scores will be high, which subsequently contributes to higher reliability.

Accordingly, it can be concluded that the reliability of the Thai version of QUALID scale is lower than that of the original version due to factors associated with the questionnaire and sample size. Nonetheless, concerning the fact that this research is a pilot study, the reliability coefficient of 0.627 is considered acceptable in reference to the concept of Williams (1994), which suggested that a reliability coefficient of 0.50 or higher is acceptable for a pilot study [36].

2. Effectiveness of the Thai version of the quality of life in late-stage dementia (QUALID) scale

This topic will be discussed under two aspects as follows:

2.1 Satisfaction towards the use of the Thai version of QUALID scale

Although the sample of this study comprised terminally ill patients who were unable to communicate and respond, data were collected from primary caregivers of the patients.

According to the results, the caregivers' satisfaction towards the appropriateness of the time spent on the questionnaire was at the highest level, and their satisfaction towards the appropriateness of the number of questionnaire items was at a high level. Since caregivers have to spend the majority of time caring for the patients, the researcher believed that the questionnaire should be concise and not time consuming. In that regard, the questionnaire was constructed to consist of only 11 items. Despite the low number of items, the questionnaire was able to capture major symptoms that should be treated in primary care. Accordingly, the caregivers

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perceived that the questionnaire is beneficial for the treatment of patients and had a high level of satisfaction towards the use of the Thai version of QUALID scale.

2.2 Benefits of the Thai version of QUALID scale

The results of this study indicated that the patients' quality of life in the aspect of calmness and comfort is positively correlated with the caregivers' satisfaction towards palliative care in the aspect of hygienic-sanitary conditions of patients. This implies that the provision of care is aligned with the goals of treatment.

Based on the foregoing results, it can be concluded that the QOL scores obtained from the Thai version of QUALID scale can be used to assess the effects of treatment and observe changes experienced by the patients so as to provide appropriate treatment guidelines for patients. Accordingly, the Thai version of QUALID scale is considered to be beneficial for the treatment of patients, as expected from the researcher.

In conclusion, the psychometric properties of the Thai version of the quality of life in late-stage dementia (QUALID) scale are of the standard in terms of validity and reliability. Moreover, the questionnaire is concise, comprehensible, and beneficial for assessment of the effects of treatment and observation of changes undergone by terminally ill patients with limited communication abilities. With that respect, the questionnaire can be used in further research.

Limitations of the Study

1. The sample of this study consisted of terminally ill patients with severe conditions and rapid disease progression. Hence, data collection could not be repeated.

2. Since data were collected among a group of inpatients—the majority of whom had a PPS level of 0%–30%—there is low variability in the characteristics of the sample.

3. Many patients were given enteral tube feeding, which directly affects their QOL scores.

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Recommendations

1. Regarding the fact that this research is a pilot study of the Thai version of QUALID scale conducted on only 30 terminally ill patients, the sample size should be increased for further research in order to achieve higher variability in the PPS level of the sample.

2. Although the questionnaire was originally developed to be used in patients with late-stage dementia, the results of this study indicate that the questionnaire can be used in preliminary assessment to serve as a treatment guideline for patients with limited communication abilities. Nonetheless, the questionnaire should be pre-tested on the respective sample prior to its actual application.

3. According to the limitation of the study on the high prevalence of enteral tube feeding in the sample which affects the QOL scores, any item on the questionnaire that cannot be assessed due to the patients' limitation should be scored zero in future research to prevent its influence on the overall QOL score.

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APPENDICES

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APPENDIX A

Palliative Performance Scale

The Victoria Hospice Palliative Performance Scale (PPS, version 2) is an 11-point scale designed to measure patients' performance status in 10% decrements from 100% (healthy) to 0% (death) based on five observable parameters: ambulation, ability to do activities, self-care, food/fluid intake, and consciousness level.

Instructions on how to use the PPSv2 can be found at:

http://www.victoriahospice.org/health-professionals/clinical-tools

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Palliative Performance Scale (PPSv2)
version 2

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity *with* Effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-

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APPENDIX B

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Siriraj Institutional Review Board
Certificate of Approval

COA no. Si 750/2017

Protocol Title(English)	: The study of psychometric properties of the quality of life in late-stage dementia (QUALID) scale Thai version in terminally ill patients: pilot study in one medical setting
Protocol Title(Thai)	: การศึกษาคุณสมบัติการวัดของแบบประเมิน The quality of life in late-stage dementia (QUALID) ฉบับภาษาไทย ในผู้ป่วยระยะท้าย: การศึกษานำร่องในสถานพยาบาลแห่งหนึ่ง
Protocol number	: 693/2560(EC4)
Principal Investigator/Affiliation	: Miss Mutita Suktham / Department of Psychiatry Faculty of Medicine Siriraj Hospital, Mahidol University
Research site	: Faculty of Medicine Siriraj Hospital
Approval date	: December 22, 2017
Expired date	: December 21, 2018

This is to certify that Siriraj Institutional Review Board is in full compliance with international guidelines for human research protection such as the Declaration of Helsinki, the Belmont Report, CIOMS Guidelines and the International Conference on Harmonization in Good Clinical Practice (ICH-GCP)

(Prof. Chairat Shayakul, M.D.)
Chairperson
- 5 JAN 2018
date

(Prof.Dr. Prasit Watanapa, M.D., Ph.D.)
Dean of Faculty of Medicine Siriraj Hospital
- 8 JAN 2018
date

Approval includes :

1. SIRB submission form version December 6, 2017
2. Proposal
3. Participant information sheet
4. Questionnaire
5. Curriculum Vitae

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APPENDIX C

เอกสารหมายเลข 3ก

เอกสารชี้แจงผู้เข้าร่วมวิจัย โดยการตอบแบบสอบถาม
(Self-Administered Questionnaire Participant Information Sheet)

เรียน ผู้ตอบแบบสอบถามทุกท่าน

ด้วยดิฉัน นางสาวมุทิตา สุขธรรม นักศึกษาปริญญาโท สาขาจิตวิทยาคลินิก คณะแพทยศาสตร์ศิริราชพยาบาล มหาวิทยาลัยมหิดล มีความประสงค์ทำวิทยานิพนธ์เรื่อง "การศึกษาคุณสมบัติการวัดของแบบประเมินคุณภาพชีวิตผู้ป่วยสมองเสื่อมระยะท้ายฉบับภาษาไทย ในผู้ป่วยระยะท้าย : การศึกษานำร่องในสถานพยาบาลแห่งหนึ่ง" ซึ่งประโยชน์ที่คาดว่าจะได้รับคือ มีแบบประเมินคุณภาพชีวิตผู้ป่วยระยะท้ายฉบับภาษาไทย ที่มีความเป็นมาตรฐาน และสามารถนำไปใช้เป็นแนวทางในการศึกษาและพัฒนาการประเมินคุณภาพชีวิตของผู้ป่วยระยะท้ายต่อไปในอนาคต

ท่านได้รับเชิญให้เข้าร่วมการวิจัยนี้เนื่องจาก ท่านเป็นผู้ดูแลของผู้ป่วยผู้ใหญ่ระยะท้ายที่รับไว้ในหอผู้ป่วยศูนย์การแพทย์กาญจนาภิเษก มหาวิทยาลัยมหิดล ในการนี้ผู้วิจัยมีความจำเป็นต้องเก็บรวบรวมข้อมูลโดยใช้แบบสอบถามเรื่อง"แบบประเมินคุณภาพชีวิตผู้ป่วยระยะประคับประคอง"ซึ่งประกอบด้วยคำถาม 4 ส่วน จำนวน 30 ข้อ ดังนี้

1. แบบสอบถามข้อมูลทั่วไป จำนวน 4 ข้อ *(ทำเมื่อแรกรับผู้ป่วย)*
2. แบบประเมินคุณภาพชีวิตผู้ป่วยระยะประคับประคองที่สื่อสารไม่ได้ จำนวน 11 ข้อ
   (ทำเมื่อแรกรับผู้ป่วย และทำซ้ำอีกครั้งหลังจากนั้น 2 สัปดาห์)
3. แบบสอบถามความพึงพอใจของผู้ดูแลผู้ป่วย ต่อการใช้แบบประเมินคุณภาพชีวิตผู้ป่วยระยะประคับประคองที่สื่อสารไม่ได้ จำนวน 6 ข้อ *(ทำเมื่อแรกรับผู้ป่วย)*
4. แบบสอบถามความพึงพอใจของผู้ดูแลผู้ป่วยต่อการดูแลแบบประคับประคอง จำนวน 9 ข้อ
   (ทำเมื่อมีการวางแผนจำหน่ายผู้ป่วย)

โดยใช้เวลาในการตอบประมาณ 30 นาที หากท่านทำแบบสอบถามเสร็จแล้วขอความกรุณาส่งแบบสอบถามกลับคืนแก่ผู้วิจัย โดยใส่กล่องคืนแบบสอบถาม ณ เคาน์เตอร์พยาบาลประจำชั้น หอผู้ป่วยศูนย์การแพทย์กาญจนาภิเษก มหาวิทยาลัยมหิดล

เนื่องจากแบบสอบถามประกอบด้วยคำถามหลายส่วน จึงขอความกรุณาให้ท่านพิจารณาตอบตามความรู้สึกของท่านให้มากที่สุด โดยข้อมูลและคำตอบทั้งหมดจะถูกปกปิดเป็นความลับ และจะนำมาใช้ในการวิเคราะห์ผลการศึกษาครั้งนี้โดยออกมาเป็นภาพรวมของการวิจัยเท่านั้น จึงไม่มีผลกระทบใดๆต่อผู้ตอบ เนื่องจากไม่สามารถนำมาสืบค้นเจาะจงหาผู้ตอบได้ ท่านมีสิทธิ์ที่จะไม่ตอบคำถามข้อใดข้อหนึ่ง หากท่านไม่สบายใจหรืออึดอัดที่จะตอบคำถามนั้น หรือไม่ตอบแบบสอบถามทั้งหมดเลยก็ได้ โดยไม่มีผลกระทบต่อการบริการและการรักษาที่สมควรจะได้รับตามมาตรฐานแต่ประการใด ท่านมีสิทธิ์ที่จะไม่เข้าร่วมการวิจัยก็ได้โดยไม่ต้องแจ้งเหตุผล

หากผู้เข้าร่วมวิจัยมีข้อสงสัยเกี่ยวกับการวิจัยหรือแบบสอบถาม สามารถติดต่อสอบถามได้ที่ **นางสาวมุทิตา สุขธรรม (ผู้วิจัย) เบอร์โทรศัพท์** 087-8262661 ติดต่อได้ 24 ชั่วโมง

หากท่านได้รับการปฏิบัติที่ไม่ตรงตามที่ได้ระบุไว้ในเอกสารชี้แจงนี้ ท่านสามารถร้องเรียนไปยังประธานคณะกรรมการจริยธรรมการวิจัยในคนได้ที่ สำนักงานคณะกรรมการจริยธรรมการวิจัยในคน อาคารเฉลิมพระเกียรติ ๘๐ พรรษา ๕ ธันวาคม ๒๕๕๐ ชั้น 2 โทร. 0 2419 2667-72 โทรสาร 0 2411 0162

ขอขอบพระคุณที่กรุณาสละเวลาในการตอบแบบสอบถาม

ขอแสดงความนับถือ
นางสาวมุทิตา สุขธรรม

1

รับรอง
โดยคณะกรรมการจริยธรรมการวิจัยในคน
รหัสโครงการ 693/2560 (EC4)
COA No.SI 750/2017
วันที่ ..... 17 .....

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APPENDIX D

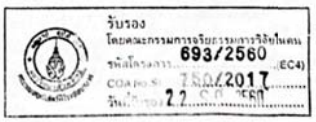
EXAMPLE OF QUALID SCALE THAI VERSION

รหัส .....

แบบประเมินคุณภาพชีวิตผู้ป่วยระยะประคับประคองที่สื่อสารไม่ได้

คำชี้แจง ผู้ให้ข้อมูลควรอยู่ดูแลผู้ป่วยอย่างน้อย 3 วันต่อสัปดาห์ และการประเมินจะสังเกตพฤติกรรมในรอบสัปดาห์ที่ผ่านมาเท่านั้น

1. การยิ้ม
    1. ยิ้มเองมากกว่าหรือเท่ากับ 1 ครั้ง/วัน
    2. ยิ้มเองน้อยกว่า 1 ครั้ง/วัน
    3. ยิ้มเมื่อกระตุ้นเท่านั้น อย่างน้อยวันละครั้ง
    4. ยิ้มเมื่อกระตุ้นเท่านั้น น้อยกว่า 1 ครั้ง/วัน
    5. น้อยมากหรือไม่เลย
2. ดูเศร้า
    1. น้อยมากหรือไม่เลย
    2. เมื่อกระตุ้นเท่านั้น น้อยกว่า 1 ครั้ง/วัน
    3. เมื่อกระตุ้นเท่านั้น อย่างน้อย 1 ครั้ง/วัน
    4. ไม่มีสาเหตุชัด น้อยกว่า 1 ครั้ง/วัน
    5. ไม่มีสาเหตุชัด มากกว่าหรือเท่ากับ 1 ครั้ง/วัน
3. การร้องไห้
    1. น้อยมากหรือไม่เลย
    2. เมื่อกระตุ้นเท่านั้น น้อยกว่า 1 ครั้ง/วัน
    3. เมื่อกระตุ้นเท่านั้น อย่างน้อย 1 ครั้ง/วัน
    4. ไม่มีสาเหตุชัด น้อยกว่า 1 ครั้ง/วัน
    5. ไม่มีสาเหตุชัด มากกว่าหรือเท่ากับ 1 ครั้ง/วัน
4. มีสีหน้าไม่สบาย หรือเจ็บปวด เช่น หน้าเหยเก คิ้วขมวด
    1. น้อยมากหรือไม่เลย
    2. น้อยกว่า 1 ครั้ง/วัน
    3. อย่างน้อยวันละครั้ง
    4. เกือบหรือตลอดครึ่งวัน
    5. เกือบหรือทั้งวัน



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