

ORIGINAL ARTICLE

**A JOURNEY FROM THE KNOWN TO THE UNKNOWN:
A QUALITATIVE STUDY APPROACH**

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Abstract

Objective: Individuals deal with dying and death differently and may not experience the same journey. We investigated Kübler-Ross' Five Stages of Grief on terminally ill patients to review the current applicability of the model among this population. The aims of this paper is to share information regarding the Five Stages of Grief, the emotions associated with the stages, and the challenges that terminally ill patients, namely those diagnosed with cancer, experience. **Methods:** Non-structured interviews were conducted among terminally ill patients located at the palliative ward for two years. **Results:** We found that terminally ill patients at the palliative ward were undergoing the Five Stages of Grief, and that the emotions associated with the stages were reported to be similar to the emotions proposed in the model and among the patients. **Conclusion:** Kübler-Ross' Five Stages of Grief is still applicable among terminally ill patients. The thoughts regarding dying and death still remain negative, therefore, the change in the myths of dying and death are required to help improve the journey towards death. *ASEAN Journal of Psychiatry, Vol. 14 (1): January – June 2013: XX XX.*

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Introduction

Individuals deal with dying and death in unique ways and not every individual experiences the same journey. The late Elisabeth Kübler-Ross proposed that the journey is made up of five stages [1] of which individuals may experience differently, such that some individuals may not stop at each and every stage, and that some may take longer than others to overcome the current stage. Dying affects both the individual and the individual's body. Individuals such as those diagnosed with terminal illness are affected physically, mentally, emotionally, socially, and spiritually [2]. The body progressively produces physical changes such as the increasing of

restlessness, agitation, confusion and need of sleep, of which are common among terminally ill patients. The psychological and emotional changes often involve extensive mental anguish and/ or emotional pain such as depression, anxiety, anger, guilt, despair, and loneliness [3] which increases the probability of social withdrawal and detachment. During this period, there is usually an increase in religious faith and spirituality among terminally ill patients as a form of coping strategy [4].

When dealing with dying and death, individuals begin to undergo preparatory grief. Preparatory grief is defined as the grieving process that terminally ill patients undergo to prepare

themselves for their departure from the world [5]. During this period, patients often revisit old memories and reflect on their past and re-live past moments or mourn for missed opportunities [6]. As part of the preparatory grief process, most patients undertake the previously mentioned Five Stages of Grief proposed by the late Elisabeth Kübler-Ross [1].

The late Elisabeth Kübler-Ross is an internationally recognized psychiatrist and author who spent most of her working life working with the terminally ill patients. She was disappointed with the standard of treatment that patients were receiving in hospitals which motivated her to focus her work on this population. From her interviews with terminally ill patients and their respective caregivers, she developed and introduced the now-famous idea of the Five Stages of Grief [1]. These stages are denial, anger, bargaining, depression, and acceptance. Denial involves the conscious or unconscious refusal to believe or accept facts, information, or the reality of the situation [1]. In reflection to terminally ill patients, the refusal to accept one's diagnosis is common. Once terminally ill patients acknowledge their diagnosis, they reacted with anger which is the second stage. Anger can manifest itself in different ways such as being angry with life, or with people especially those who are close to them [1]. Bargaining is the third stage which involves terminally ill patients asking and negotiating with the higher power for extended life. Guilt is often accompanied in the bargaining stage which causes terminally ill patients and their respective caregivers to find fault within themselves and ask what could have been done differently to prevent such tragedy [1]. During the fourth stage, which is the depression stage, terminally ill patients begin to understand the certainty of death and may detach themselves and may want to spend most of their time alone. This form of detachment, withdrawal, or isolation is a natural process of disconnecting from life which shows that the individual has begun to accept their situation [1]. Acceptance is the last stage which involves terminally ill patients with accepting their faith and awaits death [1]. Although the theoretical model

focuses on the stages that terminally ill patients may experience, it has been found to be applicable in a variety of situations that involves a significant loss [1]. Such losses may also include significant life events such as the death of a loved one, end of a relationship or divorce, or losing a favourite object.

With Kübler-Rose's Five Stages of Grief [1], both patient and their respective caregivers became more aware and understanding with the changes that the patient was currently experiencing and what changes may be predicted in the near future. However, this model was merely created to be used as a tool to help frame and identify the emotions patients may be feeling, it is not a definite guide [1]. As mentioned previously, not every individual would experience the same milestones and feel the same emotions as they journey through their terminal illness. The model was created based on the similar responses that terminally ill patients gave but there is no typical response to loss as grief is as individual as our lives [1].

The anticipation of impending death and the pain associated with the terminal illness, namely cancer, may cause patients to have psychiatric morbidities [7-9] which can be responsible for the severe changes in their mood. The prevalence of psychiatric morbidities in terminally ill patients, namely with cancer, has reported to range from 20% to 60% [10, 11] with the prevalence of major depression to range between 16% to 36% [12, 13], anxiety disorders to range between 10% to 14% [14, 15], and elevated psychological distress to range from 23% to 58% [16, 17]. Adjustment disorder and depressive disorder, however, are the two most common psychiatric diagnoses reported among advanced cancer patients [7-9, 18-20]. Common characteristics found among depressed individuals are persistent low mood most of the day or nearly every day, impairment in physical state (e.g., fatigue or loss of energy), impairment in emotional state (e.g., persistent sadness), absence of positive affect (e.g., markedly diminished interest or pleasure in activities), significant weight loss when not dieting or weight gain (e.g., a change of more than 5% of

body weight in a month) or the decreases or increases in appetite nearly every day, changes in sleeping pattern (eg., insomnia or hypersomnia), and other associated symptoms (eg., excessive worry, irritability) which impairs their daily functioning [21]. Patients too, may often feel worthless, hopeless, and helpless most of the day or nearly every day [22]. Due to the possibility of increment in irritability and agitation, some terminally ill patients may start to scold their respective caregivers and may transform into a total opposite of their usual self. The fastest way to vent out such frustration is through their respective caregivers because they know that they would never leave them alone. This is a process where the patients see themselves as a victim and start to demand attention and care to compensate what they have already lost and will lose later.

The time remaining is a common question asked by patients as well as their respective caregivers; however, timing of death is unpredictable. Due to this, it evokes feelings of insecurity and fearfulness within patients which increases their level of psychological distress especially when left alone in their rooms. Individuals may address these behaviours as “being a baby,” however, Clarke and colleagues [23] address these behaviours as symptoms of demoralization syndrome. They [23] proposed that this syndrome was associated with terminal medical illness, disability, bodily disfigurement, fear of loss of dignity, social isolation and detachment, and feelings of greater dependency on caregivers or the perception of being a burden to them. Due to their sense of impotence and helplessness, patients with the syndrome are thought to be at risk of developing depression and/ or suicidal ideations.

The journey towards death, however, is not always depressing [6] of which some individuals have found to live more positively for the duration of their remaining time. Ample evidence has shown the importance of communication in close, personal relationships such as among family members and/ or respective caregivers that has an influential role in increasing the quality of life (QOL) [24-28],

compliance to treatment, disease progression, tolerability to pain and fatigue in terminally ill patients. It has deeper significance in the QOL among end-of-life (EOL) patients [29]. Having a reliable social support network, especially in times of increased suffering or crisis, has found to have positive effects for both physical and psychological functioning [30, 31]. However, it is common among terminally ill patients to acquire low social support with respective caregivers abandoning them. This is possibly due to the elevated psychological distress that respective caregivers would have to take on when caring for their ill loved one [32, 33]. Research has suggested that deficits in social support place terminally ill patients at greater risk of experiencing loneliness and developing depression towards the EOL [34]. Due to this, some terminally ill patients often adopt religion as it has always been perceived as being significantly more reliable and stable compared to depending on people [4, 35]. According to Siegal and Schrimshaw [36], religion is often adopted for its assistance in the adjustment process by evoking comforting emotions, offering strength, facilitating meaning making and acceptance of the illness, and reducing feelings of self-blame among terminally ill patients.

A lady on her wheelchair passed by and was smiling and waving on her way out for her medical appointment and said to me; *“I have limited time left. What’s the use for me being all gloomy and sad? Why not I enjoy the time I have now?”*. Based on my observations, patients with terminal illness have different coping mechanisms due to the differences in belief, personality and social support received. Despite their condition, it was found that optimistic patients were willing to engage in conversations, had minimal regrets, and mainly worried about their children compared to their own condition. Introverts are known to keep their emotions and thoughts to themselves, whereas extroverts are more sociable by allowing them to willingly share. Extroverts may have stronger coping mechanisms as they are able to enjoy communicating with others which allows negative thoughts to be dismissed when talking

to others. Introverts on the other hand, may have other coping mechanisms such as listening to music, watching videos, and meditating. Besides that, being an introvert or extrovert and being successful in life may have an impact on the coping mechanisms of patients. As Erik Erikson has demonstrated, when an individual has achieved greatly in life they were found to be more willing to accept their death and willing to share their life stories and advise others. However, there were cases where individuals who acquired successful lives were bitter because they were holding on to their old selves and were found to constantly compare their old self with their current situation. During interviews, some patients were found to have incongruent affects and often thought of "going to Heaven". In comparison, individuals who found themselves to have wasted their lives experienced greater deal of regrets which left individuals with feelings of despair.

There were patients who had challenging lives and with the addition of the news of cancer was just their breaking point. During interviews, they expressed tremendous level of distress, guilt and dissatisfaction with life. The different characteristics and personalities of individuals were found to have an influence on their perception of things and behaviour accordingly. For example, one can use Clarke and colleagues' [37] basic cognitive model to explain the cognitive process that is activated after the occurrence of a stressful event. According to the model, after being informed of their illness, patients would be preoccupied with the negative thoughts associated with the cancer and would worry about the stigma associated with. These negative thoughts would then influence the patients' emotions and may begin to socially withdraw themselves. Unpleasant experiences and low social support were found to further strengthen these negative thoughts. When patients were overwhelmed with such thoughts, they were found to have an increased likelihood of manifesting suicidal thoughts followed by suicidal ideation and eventually attempt.

In closing, Kübler-Ross' Five Stages of Grief [1] is still applicable among terminally ill patients because it enables health care professional to identify the emotions currently experienced by terminally ill patients and categorize them accordingly to determine which stage the patients are currently in. However as mentioned previously, this model is to be used only as a tool to help frame and identify what emotions the patients may be feeling and not as a definite guide. Nevertheless, the thoughts regarding dying and death still remain negative as the unknown evokes fear and increases psychological distress among patients and their respective caregivers. Therefore the change in the myths of dying and death are required to improve the journey towards death. This can be achieved by having health professionals teach both patients and their respective caregivers to recognize the needs of the patient as well as their own needs as caregivers. With further understanding of how terminally ill patients cope with unfortunate news can help respective caregivers to deal with the emotional disturbances associated with it and meet the special needs of the dying patient. Eventually, the heart no longer beats and the breathing stops. They have completed their journey and have moved on to a better place.

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