

Vol. 5, No. 1, 2023

IIUM JOURNAL OF HUMAN SCIENCES

A Peer-reviewed Journal
ISSN 2682-8731 (Online)

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The Role of ‘Stage Theory of Bereavement,’ ‘Dual Process Model (DPM)’ and Spirituality in Dealing with Grief During Illness Experience in Cancer Patients

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ABSTRACT

When an individual experiences a terminal illness, the internalisation of the illness is based on the individual's meaning construction and the adjustments that are made to accommodate the changes that occurred due to the illness, which influences the cognitive and emotional representations of the illness perceptions of the individual (Leventhal et al., 2001). This illness experience leads individuals to experience grief. Kubler Ross's five stages of grief model grief and the Dual Process Model by Stroebe and Scut was developed as coping mechanism to understand grieving individuals. This article aims to examine and evaluate the theoretical frameworks of the Dual Process Model of Coping with Bereavement, the 5 Stages of grief by Kubler Ross, along with trying to understand the existing spiritual perspectives to deal with loss and grief experiences among terminally ill patients such as patients with cancer, to find whether a spiritual framework to deal with loss and grief exists in the literature. Examining the existing literature, the five stages of grief, and the Dual Process Model, it was found that these two models are used to cope with the loss and grief experiences. At the same time, some spiritual perspectives exist that help an individual to manage their grief. However, no existing spiritual framework helps to cope with the loss and grief experiences similar to the 5 stages models and the Dual Process Model of grief.

Keywords: illness experience, loss, and grief, Stage theory, Dual Process Model, Spirituality

INTRODUCTION

Research has shown that individuals diagnosed with illnesses such as cancer may experience various physical, psychological, and social changes, including stress, anger, nervousness, despair, worthlessness, depression, social isolation, and even the wish to die while receiving the treatment for their illness (Abdollahimohammad et al., 2019). As they go through disruptions in daily life functioning due to the illness, they also may experience different types of loss (Murray, 2005; Scambler, 2007). To explain the experiences of loss and grief, several theories could be referred to, particularly from Western perspectives. However, studies have also shown that engaging in spirituality is a crucial coping strategy in dealing with loss and despair due to illness (Willig and Wirth, 2018). For Muslim cancer patients, the spiritual framework has not been established. Therefore, there is a need to explore and develop a spiritual framework for managing the experience of loss and grief due to illness primarily based on the Islamic religious perspective.

A disease is an objective definition of observable symptoms that lead a person to a diagnosis. At the same time, Illness is a subjective definition of an experience that differs from person to person (Scambler, 2007). The individual's internalisation, construction of meaning, and adjustments made to accommodate the changes that occur (Leventhal et al., 2001) due to the illness is the illness experience (Scambler, 2007). According to Leventhal et al. (2001) common sense model of illness perception, an

individual builds the knowledge of illness perception based on their previous experiences, information that they have had about the disease through pamphlets and other mediums along with the outcome of prognosis made due to the actions they have taken to remove the illness in the past. For an instant an individual having a headache without any other related symptoms may take a painkiller, which helps the individual get rid of the headache. Hence the schema for this illness experience is created for the individual, and the need to show it to a professional is avoided when the same situation arises later. Hence the individual’s illness perception is influenced by their emotional and cognitive representations of the illness (Leventhal et al., 2001; Murray, 2005; Scambler, 2007).

In support of this view, Petrie and Weinman (2006) state that this illness experience influences emotional reactions, behavioural changes, and an individual's coping strategies. During this process of illness experience, the individual develops a mental model that helps the individual make sense of the illness experience (Petrie and Weinman, 2006). Leventhal et al. (2001) developed a common-sense mental model of illness experience by using five dimensions of illness experience.

Common Sense Model of illness perception explained by Leventhal et al. (2001)

The 5 dimensions that influence an individual's illness perception (Leventhal et al., 2001) are explained below and given in Table 1. According to Leventhal et al. (2001), the Coping mechanisms of individuals are built based on these five dimensions.

Table 1: The 5 dimensions of the common-sense model.

Dimension	Factors that influence	Description
Dimension 1	Identity of the illness	Connection of the illness experience with the symptoms experienced.
Dimension 2	Timeline	the measure of prognosis with the duration of illness experienced.
Dimension 3	Causes	figuring out the reasons why the individual had such a diagnosis.
Dimension 4	Consequences	the individual is forecasting the end of the illness, and what it is going to be like.
Dimension 5	Controllability	figuring out the prognosis of the illness, its curability, and controllability of the illness.

Note. The 5 dimensions of the common-sense model that influences an individual's illness perception are mentioned by Leventhal et al. (2001).

Based on this common-sense model of self-regulation, the schematic representations developed by the individual concerning the illness experiences are influenced by the dimensions of illness identity, the timeline of the illness, the cause of the illness, and controllability of the illness, the individual’s ability to self-regulate the illness experience and develop coping responses depends on these dimensions.

An individual’s cognitive schematic responses to cope and self-regulate the illness experiences are influenced by these five dimensions of the common-sense model of self-regulation. When an individual experiences an illness, different types of losses can be experienced as the individual understands disruptions the illness has caused in daily functioning (Murray, 2005; Scambler, 2007). In addition, Murray (2005) explains that individuals experiencing loss display an array of symptoms which could begin from physiological symptoms such as headaches to more severe psychological symptoms

such as depression, which are reactions to loss experiences known as grief. However, Hatamipour et al. (2015) state the importance of spirituality in developing strategies to cope with the disruptions that occur in difficult times. Where else James and Well (2003) explained the role religion played in developing coping mechanisms to deal with loss and grief experiences. Spirituality as a means of coping with loss and grief is a novice area for Islamic scholars requiring more research.

Early theorists like Kubler-Ross tried to understand the coping strategies individuals experience during loss and grief experiences. Kubler-Ross developed a theoretical model to understand this grief and coping mechanism during a loss experience known as the five stages of grief theory by Kubler Ross (Martin and Privette, 1989). Along with this came many other perspectives to understand the coping mechanisms of an individual's loss and grief experiences. Another grief work theory is The Dual Process Model of Coping with Bereavement (DPM) (Stroebe and Schut, 1999).

This article emphasises an evaluation of the theoretical frameworks of the Dual Process Model of Coping with Bereavement (DPM) (Stroebe and Schut, 1999), the five stages of grief by Kubler Ross (Martin and Privette, 1989), along with trying to understand the spiritual perspectives to deal with loss and grief experiences among terminally ill patients such as patients with cancer.

LITERATURE REVIEW

Effects of a Terminal Illness on Developing a Loss Experience

Terminal illnesses such as cancer bring about emotional, physical, social, and spiritual changes in individuals experiencing the illness. Studies done on head and neck patients cancer found the facial disfigurements these patients go through due to surgeries, radiation, and other forms of treatment, such as consumption of painkillers that results in absenteeism to work, loss of self, loss of job and loss of finances (Rhoten, Murphy and Ridner, 2013). In a study of 280 patients with cancer, the patients had body image issues, speech difficulties, eating difficulties, and cognitive and behavioural challenges, which led to a sense of loss of self, loss of social interactions, and loss of health (Fingeret et al., 2013). Themes such as liminality, holding on to life, life as a cancer patient, and trauma are themes found in a meta-analytical study of 23 published phenomenological studies between 2011 to 2016 (Willig and Wirth, 2018). These studies also showed that patients with cancer anticipate future scenarios and use positive thinking and the involvement of spirituality to cope (Willig and Wirth, 2018) with the anticipatory grief experiences (Hottensen, 2010) manifested due to the multiple loss experienced by the cancer patients.

When individuals experience illness, disruptions occur in seeking treatment (Warren, 1978). Disruptions such as irregular menstruation, mastectomy, infertility, and loss of femininity were found among women with breast cancer who underwent chemotherapy, radiation, and surgery as means of treatment for cancer (Silva as cited in Carvalho et al., 2016). The above viewpoint was supported by Zaider et al., (2012), in their study of 75 male patients with prostate cancer, found a loss of masculinity, perception of loss of sexuality, loss of identity, loss of self, and change of role. In another study, a clinical observation of 104 patients with cancer found they experienced orofacial and xerostomia changes that led to the inability to talk due to pain, resulting in the loss of social interaction and social life (Fischer et al., 2014). These studies are supporting that individuals who have experienced cancer as a terminal illness experience different types of losses such as loss of identity, loss of role, financial loss, loss of social life, and loss of health and many have experienced multiple losses.

The Dual Process Model and Stage Theory as a Coping Mechanism for Loss and Grief

The dual Process Model was developed by Stroebe and Schut (1991) to understand the coping mechanisms of a grieving person. The model helps to understand the oscillation of the individual from the world before the loss experience to the world after the loss experience (Murray 2005). Chronic illness diagnosis alters individuals' assumptions and perceptions about the world and self, resulting in fragmentation of self-identity and alienation (Bertrand, 2021). In the autoethnographic study to understand how writing, combined with the dual process model, helped Fibromyalgia (FM) patients found in the writings as a mechanism to process grief experience and adapt to the circumstances that have been changing, the individual experiencing the illness shifts from loss orientation which was explained as the first story to restoration orientation which was known as the second story (Bertrand, 2021). The participants described, through their writings, that in response to coping with their grief, they expressed about the world that was before the loss experience and how they have made alterations and adjustments to the world that is now after the loss experience.

On a similar line, the study conducted to explore mothers' grief experiences and coping mechanisms for two years after losing children in an earthquake found through six in-depth interviews that these mothers were suffering from intensive grief and they coped with their loss experiences through the oscillation between the loss orientations and the restoration orientation of the dual process model (Chen et al., 2019).

In a longitudinal cohort study by Maciejewski et al. (2007), recruiting 233 individuals bereaving found consistencies with the stage theory in coping with bereavement except for disbelief. According to Maciejewski et al. (2007), the initial dominant indicator of grief was not disbelief. In the initial months of loss, experience a high degree of acceptance was seen even in natural death cases. On a different note, acceptance was lower among participants who were bereaving due to the death of the loved one to a terminal illness within 6 months of receiving a diagnosis in comparison to participants who were bereaving the death of a loved one to a terminal illness for more than six months. Maciejewski et al. (2007) also suggest that this acceptance of death could be due to prognostic awareness resulting in the opportunity to prepare for the death of the loved one allowing the participant to adjust to the loss experience psychologically. It was also found that the five stages were utilised in the process of coping with bereavement (Maciejewski et al., 2007)

In the case study of a woman's emotional journey of colon cancer diagnosis and treatment Wilson and Fletcher (2002) aimed to find out whether Kubler Ross's stages of grief theory paralleled with her experience, the extent model applied to her, and whether the new stages exist, according to Wilson and Fletcher (2002), the five stages, denial, bargaining, anger, surrender, and acceptance, existed. These stages frequently overlapped or simultaneously occurred, validating the stages of the grief theory of Kubler-Ross.

Spirituality as a Mechanism to Cope with Loss and Grief

For patients with cancer, one of the mechanisms to manage feelings of despair and loneliness is spirituality (Surbone and Baider, 2010). The meta-analysis by Willig and Wirth (2018) supports this phenomenon of engaging in spirituality as a crucial coping strategy. Spirituality is a concept used either with the existence of religious aspects or a lack of religious aspects. However, this dichotomy exists among researchers (Basri et al., 2015) who view spirituality as the inner Islamic dimension suggesting that spirituality cannot exist without religion. Based on Islamic teachings, the road map of life is prescribed through religious acts such as prayers and *dhikrs*. The continuous relationship between Allah

and many other such acts builds the essence of spirituality in Islam (Ahmad et al., cited in Basri et al., 2015).

Based on the definitions of spirituality as the attachment with God, the Iranian study by Hatamipour et al. (2015) using 18 patients with cancer found (1) connection; interpersonal connection and relationship with the creator, (2) seeking peace; the wish for peace in life, (3) meaning and purpose; to have a purpose in life and a meaning to live life, (4) transcendence; the communication one has with the creator are the themes that were found for the participants to cope with the experiences of grief. A cognitive-behavioural framework by James and Wells (2003) suggested two methods of how religion assisted the mental health wellness of patients and how the self is regulated. According to James and Wells (2003), religion was the guiding factor of life events, religion assisted in giving meaning to stressful and adverse life events, and religion helped to develop the understanding of control and predictability of life events. Religion also gave self-regulation opportunities- through direct actions and thoughts of ourselves, religion provides this opportunity to self-regulate (James and Wells, 2003). In addition, religion also gives coping abilities through primary and secondary coping (James and Wells, 2003). Many studies conducted on patients with terminal illnesses such as cancer have found the involvement of spirituality has reduced distress, increased life quality, increased the ability to adjust to the situation, and increased psychological wellness in comparison to individuals who were not involved in spirituality (Riley et al., 1998).

METHODOLOGY

The content analysis of the two theories of grief, the dual process model and 5 stage theory, highlights some mechanisms individuals adopt to manage their loss and grief experiences during illness experience. Likewise, some studies that have been analysed in this article suggest that religious spirituality also assists individuals in developing coping strategies to overcome loss and grief experiences during illness experiences. In addition to these analyses, religious scriptures of Islam, such as the Quran, gives a foundation for religious and spiritual components to develop coping mechanisms for individuals experiencing loss and grief. Though Quran gives the foundation for coping mechanisms and some studies suggest that spirituality assists in developing coping mechanisms for loss and grief experiences, whether Islamic spirituality assists individuals to deal with loss and grief experiences during illness experiences such as cancer has been scarcely studied. Therefore, a grounded theory design can explore this phenomenon and establish an Islamic spiritual framework to deal with loss and grief experiences during illness experiences such as cancer.

Conceptualisation of Kubler-Ross's Stage Theory of Bereavement and Dual Process Model of Grief

To understand the grief process, many theorists have developed models, such as Kubler Ross 'stages of bereavement, Strobe and Schuts' dual process model, Bowlby's attachment theory, and the Tear model developed by Worden in 1991 are some such models. Though these are not spiritual models, this article examines the concepts of Kubler-Ross's stage theory and Strobe and Schuts' Dual process model, as these models are taken as the theoretical framework for the future build-up of the Islamic spiritual model.

The Five Stages of Grief by Kubler Ross

Kubler-Ross gave the five-stage theory of grief for bereavement based on her work with terminally ill patients in her book on death and dying (Kubler-Ross and Kessler, 2014). The five stages are explained below.

Stage 1 - Denial and Isolation

This is the initial reaction of an individual experiencing loss and grief (Kubler-Ross, 2009). When an individual experiences excruciating painful loss experience, the mind uses denial as a defense mechanism to refuse to accept this painful experience (Kubler-Ross and Kessler, 2014). Denial can be experienced by friends and family of an individual experiencing a severe health issue, their fears could blind-sight them, which blocks internal and external information from passing through (Corey and Corey, 2010). Hence, they cannot understand or provide the support the individual suffering from the illness needs (Corey and Corey, 2010). Some initial reactions or statements made are "This cannot be true" or "This cannot be happening to me" (Kubler-Ross and Kessler, 2014). Denial is seen mainly in the initial stage; later, isolation becomes more prominent (Kubler-Ross, 2009).

Stage 2 - Anger

This is an individual's reaction to the loss experience, which includes resentment, rage, envy, and blaming other external factors for making them go through this experience (Corey and Corey, 2010). As the individual was unable to prevent the loss, feelings of uncontrollability take over, making the individual randomly displaced and project feelings of anger on the environment, hindering other's ability to manage this individual difficult (Worden 2009). Due to the uncontrollability of the loss experience, previous statements of "This cannot be happening to me" change to "Why me?".

Stage 3 - Bargaining

Even though an individual experiences denial and anger in the initial stages of loss and grief, they enter this stage with the belief that they could come to some form of agreement with the higher power or their creator so that they can be successful in preventing the inevitable from happening (Ross as cited in Martin and Privette 1989). Especially for people experiencing terminal illness and loss due to health issues, this stage becomes very helpful as in this stage, the individual tries to regain some form of control over their situation (Kyalo and Ochanga, 2011). The individual comes into this stage believing that good behaviours come with a prize hence if good behaviour is manifested, the undesired result may be prevented (Kyalo and Ochanga, 2011). Bargainings are the individual's secretive, implicit vows to the higher power or the creator (Kubler-Ross, 2009). People use different bargaining methods depending on their individual belief (Kyalo and Ochanga, 2011). The bargaining of an individual experiencing a terminal illness like cancer may be like this " If my test results show that I have beaten cancer, I will feed 40 people".

Stage 4 - Depression

When an individual suffering from a terminal illness like cancer has to undergo several surgeries and be hospitalised for a prolonged period (Kubler-Ross and Kessler, 2014), eventually, the denial and feelings of anger that were harboured fade away, giving rise to feelings of loss (Corey and Corey, 2010). The experience of loss has many facets where individuals experience different forms of loss; where some individuals may experience one form of loss, and others may experience multiple losses such as loss of self, loss of identity, loss of roles, loss of job, loss of social life and etcetera (Isaksson et al., 2007). Due to these losses, feelings of guilt and sadness experienced by the individual depression prevail (Isaksson et al., 2007).

According to Kubler-Ross, 2009 two forms of depression exist, (i) reactive depression (ii) Preparatory depression, and it is not necessary for all individuals experiencing depression to go through

these two forms of depression. According to her, some people may be experiencing only one form of depression (Kubler-Ross, 2009). Individuals in this stage may use statements like "Let me be alone."

Stage 5 -Acceptance

This is the last stage of this model. When individuals reach this stage, they are neither depressed nor angry about what life has put them through, and as they realise the truth of life, acceptance of life's reality takes place (Martin and Privette, 1989). This is the stage of impending mourning loss, the impending loss of meaningful attachments the individual has with the people and places as they contemplate death (Kubler-Ross, 2009). Individuals in this stage of grief use statements like "nothing lives forever" or "we all will die one day" When we try to understand Kubler-Ross's stages of bereavement, it is essential to know that an individual does not go through the stages in numerical order, one needs to understand that an individual may skip some of the stages. Another may not experience some of the stages of this model (Ross as cited in Martin and Privette, 1989).

The Dual Process Model

The Dual Process Model (DPM) was developed to empirically validate and support grief work, as traditional theories lacked this empirical validation and support (Stroebe and Schut, 1999; Stroebe et al., 2017). As the Dual Process Model tries to understand the coping mechanisms of the grieving individual, the model uses a simple two dimension of stressors known as the loss orientation stressor and the restoration orientation stressor (Stroebe and Schut, 1999). The loss-oriented stressor is the dimension in which the individual's focus of the loss experience is solely on the aspects associated with the deceased or the illness, crying, yearning for the deceased, the negative feelings associated with the environment, and the relationship they have had with the deceased (Stroebe and Schut, 1999; Stroebe et al., 2006) where else, in the restoration oriented stressor dimension, the individual focuses on the adjustments that have been taking place to secondary losses. This reorganisation must create new roles and identities, feelings of relief, pride versus fear, and despair (Stroebe et al., 2006). According to Stroebe and Schut (1999); Stroebe et al. (2006), it is the oscillation between these two dimensions that is most crucial, as it is the oscillation from the loss-oriented stressor to the restoration-oriented stressor, the coping mechanism adopted by the grieving individual.

According to Stroebe and Schut (1999), this oscillation to the loss-oriented stressor decreases as the passage of time increases. One may encounter some dialogues from a grieving individual during loss orientation and restoration orientation. A study that supports the DPM model by Tay and Lee, 2022, explained how the individual grieving experiences these two dimensions.

Loss orientation dialogue in which acute reaction of grief and immense grief experienced by the bereaving caregiving (Tay and Lee, 2022)

The guilt that I wasn't there (during his last moments). In the last conversation that we had, (I said) 'I'm exhausted. Please don't disturb me.'... Since I was exhausted, he decided not to disturb me forever. I cried... (because) that was a mean thing to say at that moment... I've said that many times to him... (but) it was nothing because he didn't die. But that night, that was the last conversation that we had. In the morning, he wasn't conscious anymore. He was breathing through the machine. (p.9)

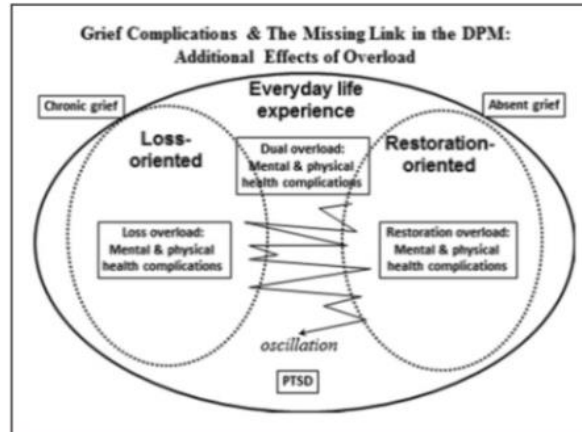
Restoration orientation dialogue of a caregiver grieving the loss of a spouse avoiding reminders of the loss experience, as avoidance, is another form of coping (Tay and Lee, 2022).

Those places that would equate to when he was in his last days were harrowing (reminders) for me. That was why when I had the time... (I) quickly got rid of all those things that would remind me of him... I packed all his clothes... (and) given them away. But, of course, I keep his photos there. (p.11)

Below is the as figure 2 explains the Dual Process Model with bereavement.

Figure 2

Two dimensions of DPM.



Note. The Explanation of Loss orientation and Restoration orientation of the dual process model with the overload component is taken from Stroebe and Schut (2016).

Spiritual Perspective on Loss and Grief

Spirituality is the aspect of the life of a human being that gives hope for any adverse life situation (Stanton et al., 2002), suggesting that hopefulness increases as the individual’s religiosity increases. A longitudinal study recruiting women with breast cancer found an association between religious coping with the betterment of psychological wellness and adjustments (Carvalho et al., 2016). In a study conducted at an Intensive care unit (ICU) of a hospital in Pakistan, the researchers played surah Rahman from Quran three times a day in ICU for patients with cancer, attempted suicide, and suffering from hepatitis (Rasheed, 2019). Doctors found that these patients' recovery speed increased, and all the patients were later discharged from ICU after making a full recovery (Rasheed, 2019).

As mentioned in this article, James and Wells (2005) emphasise religion's role in providing coping mechanisms to people experiencing loss. In Islam, it is the belief an individual holds on to as Allah has revealed in the Quran that these calamities, difficulties, and experiences of loss are from Allah and it is a form of test that Allah has bestowed upon the person; the following verses are taken from an English translation of Quran by Ali (2003):

وَلَنَبْلُوَنَّكُمْ بِشَيْءٍ مِّنَ الْخَوْفِ وَالْجُوعِ وَنَقْصٍ مِّنَ الْأَمْوَالِ وَالْأَنْفُسِ وَالثَّمَرَاتِ ۗ وَبَشِّرِ الصَّابِرِينَ.

“And we will try you with something of fear and hunger, and loss of wealth and lives, and fruits; but give glad tidings to the patient” (The Holy Qur’an 2:155)

الَّذِينَ إِذَا أَصَابَتْهُمُ مُصِيبَةٌ قَالُوا إِنَّا لِلَّهِ وَإِنَّا إِلَيْهِ رَاجِعُونَ .

“Who, when a misfortune overtakes them, say, 'Surely, to Allah we belong and to Him shall we return.’” (The Holy Qur’an 2:156)

Furthermore, verses from Quran emphasise that Allah does not let a person go through difficulties that they could not bear, and to get over the pain and the loss and hardship,

لَا يُكَلِّفُ اللَّهُ نَفْسًا إِلَّا وُسْعَهَا .

“Allah burdens not any soul beyond its capacity.” (The Holy Qur’an 2:286)

Allah reveals in Quran to pray to Allah to find solace to the aching hearts.

يَا أَيُّهَا الَّذِينَ آمَنُوا اسْتَعِينُوا بِالصَّبْرِ وَالصَّلَاةِ إِنَّ اللَّهَ مَعَ الصَّابِرِينَ .

“O ye who believe! seek help with patience and Prayer; surely, Allah is with the steadfast” (The Holy Qur’an 2:154)

These verses from Quran suggest that a person experiencing a loss is a test from Allah, and Allah will not burden a soul beyond its capacity the ultimate way to move forward and get over the grief is to say that they are from Allah and to Allah they will return, and to have patience and seek patience through believing in Allah and praying to him. Therefore, exploring and scientifically examining how these beliefs help individuals cope with their loss and grief experiences during a terminal illness is crucial.

The Conceptual Framework Diagram

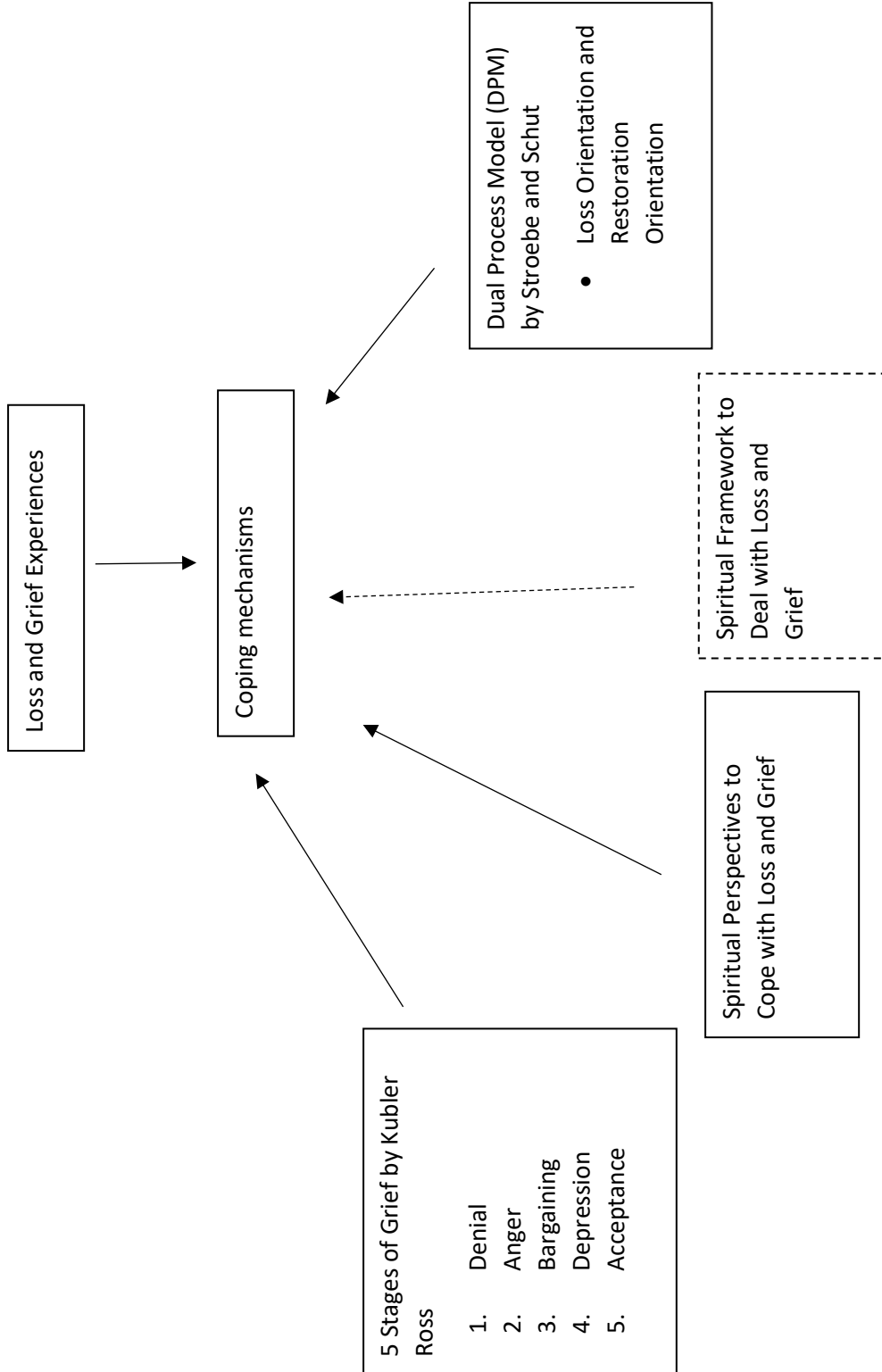
It is understood that the five stages of grief and the Dual Process Model help an individual cope with their loss and grief experiences. Though there is no spiritual framework or theory to cope with the loss and grief experiences, the literature suggests that there are spiritual perspectives that help an individual to cope with loss and grief experiences. Figure 1 shows the conceptualisation of the theories discussed above.

FINDINGS

The findings of this conceptualisation article and its literature review show that the five stages of grief by Kubler Ross and the Dual Process Model (DPM) model of Stroebe and Schut are used to cope with the loss and grief experiences. Similarly, spiritual perspectives exist that helps an individual to manage their loss and grief experiences. However, no individual spiritual framework or theory exists, such as or similar to the existing theories of bereavement or grief found in the literature. Hence, based on the above models, the framework for the spiritual model in dealing with loss and grief experiences during illness experiences is as follows:

Figure 1

Conceptualisation of five stages of grief theory, Dual Process Model, and the spiritual perspectives to cope with loss and grief.



CONCLUSION

This article has attempted to understand how an individual's illness experience is developed, which leads to the development of an individual's loss and grief experiences. Further, it has attempted to highlight the theories, such as the five stages of grief theory and the dual process model's role in helping individuals to cope with loss and grief experiences. The article has examined some aspects of spiritual coping and religious beliefs that need to be scientifically established as a coping mechanism for individuals experiencing loss and grief due to a terminal illness.

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