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RESEARCH ARTICLE

A SCOPING REVIEW OF THE ROLE OF SPIRITUALITY IN DEALING WITH LOSS AND GRIEF AMONG CANCER PATIENTS

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Abstract

Cancer is one of the most commonly occurring terminal illnesses across the globe affecting millions of people and their loved ones. When someone experiences such a terminal illness, the experience is negatively perceived creating a loss and grief reaction which affects the person's psychospiritual aspects of life. Many patients and caregivers adopt various coping strategies including spiritual concepts. Hence this study aims to review existing literature to understand the role of spirituality in dealing with the loss and grief experiences of cancer patients. A search on Ebsco Discovery Service was conducted for peer-reviewed, English, full-text academic articles between January 2017 to December 2020. A total of 602 articles were found, out of which 13 articles were accepted after screening for eligibility. All these 13 articles are reported in this paper. From the 13 articles major 4 themes were extracted which are, belief in God, having faith and hope, Spiritual acts, and comfort through a higher power.

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Introduction:-

Cancer is one of the most feared diseases in the world and a cancer diagnosis is viewed as a death sentence (The American Cancer Society, 2003). In the 2018 report of the World Health Organization (WHO), 18.1 million people were diagnosed with cancer in the world (WHO,2018). Since cancer is a terminal illness, for people who are diagnosed with cancer, the caregivers and family develop various emotional reactions (MacCoyd & Walter, 2016). One such reaction to such a diagnosis is loss and grief (Bowen, 1978). Loss is defined as a negatively perceived event or situation that brings about changes to the person's biopsychosocial aspects and relationships (Murray, 2005) while grief is defined as the reaction of a person towards their loss experience and the process of adapting to the loss (Murray, 2005). Loss and grief are an area that has been studied and reviewed by many researchers. Some theories have been developed to understand what and how an individual grieves after a loss is experienced and other theorists have tried to understand the different types of losses a person experiences. One commonly used theory to understand the grieving experiences of an individual is Kubler-Ross's stages of grief theory (Martin & Privette, 1989). Kubler-Ross has explained in her theory the stages an individual experiences during grief and how an individual moves from one stage to the other (Kubler-Ross, 2009).

Patients with cancer experience loss and grief due to the many different experiences they go through. Cancer is a disease that makes an individual go through many psychological and physical challenges due to the diagnosis of the disease or the treatment of the disease. It was identified in research that patients with cancer experience alopecia, constipation, and hand-foot syndrome (De Francia et al., 2021). Similarly, Fingerete et al (2013) stated that patients

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with cancer experience speech difficulties, and behavioural and cognitive difficulties along with difficulties consuming food due to the treatment of the disease. In addition, head and neck patients with cancer experience an impairment of oral functioning, pain, dry mouth, dysphagia, and difficulty in chewing due to the disease and its treatment (Carl-Otto Brahm et al., 2021). Patients with cancer also experience psychological effects in addition to the physical challenge, self-blaming, feelings of sadness, fear, uncertainty (Komariah, 2021), and body image issues (Bakht & Najaf, 2010; Fingeret et al., 2013; De Frank et al., 2007) are some of the psychological effects of cancer.

To manage these loss and grief experiences, patients of cancer face due to the physical and psychological challenges experienced by them, and they adopt different coping strategies. In addition to understanding the lived experiences of loss and grief, many researchers have explored different coping mechanisms utilized by individuals to overcome their grief experiences. It was mentioned by Martine and Privette (1989) that people utilize different coping strategies which include behavioural, emotional, or cognitive forms of coping strategies. One such coping strategy adopted by grieving individuals is the stages of grief by Kubler – Ross (2009). Similarly, Strobe and Schut (1999) state that to cope with the grief experiences an individual oscillates between the loss orientation and the restoration orientation; which are the two dimensions of their Dual Process Model. As mentioned by Stroebe and Schut (1999) this oscillation between the two orientations provides grieving individuals an opportunity to move away from their loss experiences, heartaches, the yearning and to focus on the tasks on their hands and gradually move forward with life. In addition, James and Wells (2003) emphasized the role of religion as a coping mechanism for loss and grief experiences. According to James and Wells (2003), religion is the key provider of primary coping strategies; which is an individual involving themselves in religious acts such as praying to God or the divine power to change the situation they are in. Furthermore, James and Wells (2003) stated that religion also offers secondary coping strategies for an individual; which is the individual changing their self through cognitive restructuring, changing perceptions, and believing that in the end, it is the will of God for them to be in the situation they are currently in.

Though much research explores on loss and grief experiences and the coping mechanisms adopted by cancer patients, few researches explain how spirituality helps to cope with loss and grief experiences among cancer patients. Hence, the rationale of this review is to identify what are the spiritual methods used that help to deal with the loss and grief experiences and it is aimed to review existing literature to understand the role of spirituality in dealing with the loss and grief experiences of cancer patients. This review will further support the existing gap in an Islamic Spiritual framework to deal with loss and grief identified by Ismail et al (2023).

Methods:-

A systematic search of the literature was conducted by using the Ebsco host. The following strategy was applied to search for existing literature. In the advanced search category of Ebsco host the terms “Spirituality” or “religion” or “faith” or “belief system” were entered "loss" and "grief" terms were entered and "cancer patients" or "oncology patients" or “patients with cancer” were entered. After selecting full text and peer-reviewed articles, the language set 'English' was selected along with selecting articles available in the library collection. Furthermore, the year set from January 2017 to December 2022 was selected. The search was further limited to only academic journals and excluded personal reviews, dissertations or theses, country profiles, and personal reviews. Since the study was aimed to review qualitative research, the search was further limited to qualitative research in the subject section and excluded meta-analysis, systematic reviews, quantitative research, or mixed mode of research designs.

Figure 1 gives an overview of the search selection flow chart adapted from PRISMA.

Furthermore, inclusion and exclusion criteria for articles are given below

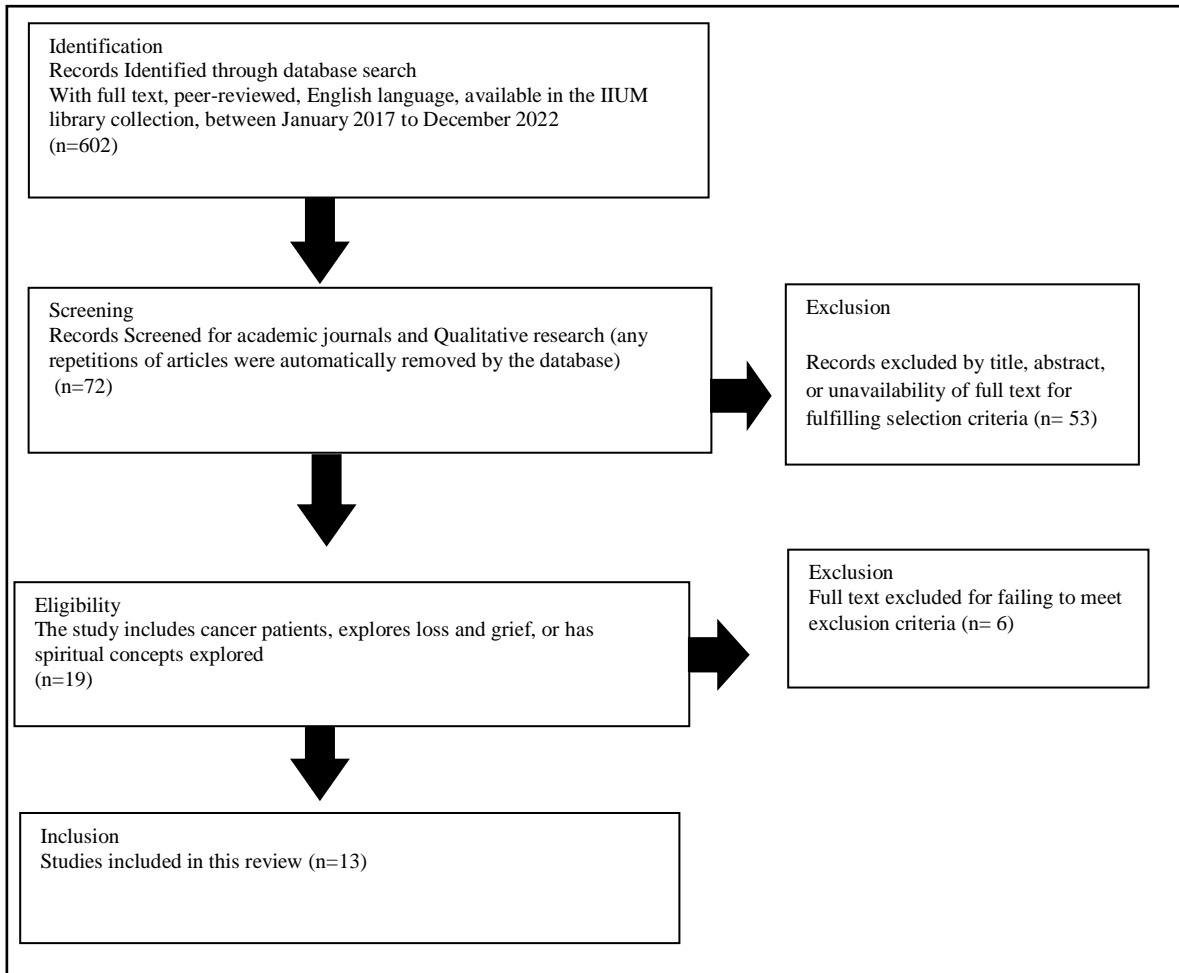
Inclusion Criteria of Studies

1. Any research that has used patients diagnosed with cancer, patients undergoing cancer treatment, patients that have already survived cancer, or have died due to cancer information, or recruited the above-mentioned categories of people as participants
2. Loss and grief components are included
3. Either spirituality concepts explored or found as results of the study
4. Articles published between January 2017 to December 2022.
5. Articles in academic journals
6. Articles that are qualitative in nature
7. Articles that are peer-reviewed and published in the English language
8. Articles that have full text available in the IIUM library collection

Exclusion Criteria of Studies

1. Opinion pieces, books, edited books, chapters of books, narrative reviews, dissertations, and conference papers are excluded.
2. Any publication that does not use patients diagnosed with cancer, patients undergoing cancer treatment, patients that have already survived cancer, or have died due to cancer information are excluded
3. Studies conducted on service providers of cancer disease
4. Any article other than in English language is excluded.

Figure 1:- PRISMA flowchart that shows the process of literature search and selection of studies to be included in this review.



Characteristics of included studies

The characteristics of the included studies are given in the extraction table attached in Appendix A. All the studies utilized in the search are qualitative research that has been published between January 2017 to December 2022. A total of 276 participants were included in this search by using the 13 published articles.

Findings

In the literature reviews some common themes across the studies were found as well as differing themes. The extraction table of the themes of the studies used is attached as Appendix A. Though many sub-themes were found only the main themes are reported for this paper. The common themes found on the role of spirituality in dealing with loss and grief are described next.

Belief in God

It was found that the participants had the belief that the disease is from God, it is the way God strengthens their relationship with God, and through the disease, they are encouraged to praise God (Baran & Baran, 2022). It is through this belief that the acceptance of the illness and the reality takes place making them believe that death is inevitable (Baran & Baran, 2022; Raju & Reddy, 2018) and death is not always negative; death is a form of relief for the suffering patient and being grateful and having gratitude feelings towards God and others around the grieving individual is a form of support they perceive. (Beng et al., 2021).

When grieving individuals understand spiritual and existential suffering, they start to reframe and make meaning out of their experience. It is through this spiritual and existential suffering they learn the purpose of suffering and the meaning of life (Benites et al., 2021). It was also found that believing in a higher power assisted in overcoming or dealing with the emotions of sadness, worry, nervousness, and fear (Raju & Reddy, 2018).

Having faith and hope

One of the primary coping methods found in the studies was staying positive, and this positive attitude was achieved by staying interconnected with the fight for surviving cancer and having feelings of hope (Glaser et al., 2020). It is believing that the ultimate power lies with God and the ultimate decision is made by God and the rest such as the medical professionals and others in the environment are mere instruments of God and tools provided by God to take care of the patient and provide a cure (Glaser et al., 2020). It is having faith in religion that assisted the family members to adjust and take up the new role in their families (Beng et al., 2021) and it is this spiritual faith that facilitated the feelings of 'hope' to cope for parents who were experiencing terminal illness of childhood cancer children during their end-of-life experience (McCaughan et al., 2021). Furthermore, the participants felt supported when they had faith in spirituality or religion (Beng et al., 2021) and to overcome or to cope with their grieving experiences having faith, hope, and praying to God were the helping factors (Lokkerberg et al., 2020).

Spiritual acts

Praying to a higher power (Cai et al., 2020; Raju & Reddy, 2018; Abu Sharour, 2019), being involved in religious or spiritual acts, and visiting worshipping places like shrines (Abu Sharour, 2019) were ways adopted to cope with the grieving. It is through engaging in such religious activities by the patients before their death, that helped them to have the understanding of their intrapersonal and interpersonal connections, and the motivating factor for the patients to live a decent life (Hamilton et al., 2017). It is through these experiences the patients developed the need to build a connection with God (Hamilton et al., 2017) which has led participants to seek comfort through praying (Cai et al., 2020) and has helped them to seek meaning during their illness experience along with giving them an increased sense of control over the situation (Abu Sharour, 2019).

Comfort through a Higher power

Religion and spirituality had a vital role in dealing with loss experiences as it was the religion that gave participants comfort, the strength they needed to face the calamity they were confronted with and it was religion and spirituality that equipped these participants with different tools to overcome their challenging experiences (Hayden & Dunnes, 2020). The comfort received through the higher power by praying, and believing in the supreme power (Cai et al., 2020) and religious practices (Hamid & Khan, 2021) gave the support the participants wanted. In addition, seeking spiritual healers (Hamid & Khan, 2021) assistance was also comforting for the participants. It was also found in the studies that the participants believed that God had absolute power, was non-judgemental, had limitless knowledge, and knew best, hence, it is God that helps them to manage their pain (Hamilton et al., 2017). It is due to these beliefs that the participants seek comfort through a higher power by talking with God and believe that death is a temporary state of nonbeing (Hamilton et al., 2017). Therefore, preparing for death is helpful to the patients as it allows them to complete the unfinished business such as writing up their will and marriages of children (Raju & Reddy, 2018). It was also found that faith in religion, engaging in religious communities, traditions, and rituals, and having religious beliefs along with the integration of their spiritual experiences helped in their transcendence and hope (Wikert et al., 2022).

Discussion:-

This narrative-style literature review aimed to understand the role of spirituality in dealing with loss and grief in cancer patients, and their caregivers in qualitative studies between the year January 2017 to December 2022. The review found many components that contributed to the coping strategies of individuals and four concepts or themes

which are belief in God, having faith and hope, involvement in spiritual acts, and comfort through a higher power were identified as methods of spiritual coping.

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Appendices

Appendix A:- Extraction Table.

Study	Participants	Subject Characteristics	Design	The outcome of the collected data
Study 1 (given in reference number 4)	12	6 Mothers 6 Fathers All parents had cancer-diagnosed children -Children aged between 7-11 years -Children diagnosed with cancer more than 6 months -Children were taking cancer treatment of chemotherapy - Children were treated in Dicle University's Paediatrics Hospital Haematology	-A qualitative design with a phenomenology approach - used structured interviews before diagnosis and after hearing of the diagnosis for the first time.	- Disease is an act of God - the disease was the act of God to encourage them to praise God

		Clinic		
Study 2 (Given in reference number 5)	20	-Above 18 years -Active family caregiver of a cancer patient admitted to palliative care at the university -Malaya Medical Centre -The caregiver is coping well with the caregiving	A qualitative study with face-to-face semi-structured interviews	-Accepted the new role in the family by understanding and accepting - Having faith in religion -Support is achieved by having faith Acceptance Death is inevitable - Death is a relief for the patient from their suffering -Support is achieved through having feelings of gratitude to God and others
Study 3 (Given in reference number 6)	18	-Above 18 years -Family caregiver (spouse, relative, or friend) - Provide care to an advanced cancer patient at end of life hospitalized - - Have an awareness of the prognosis of the patient's cancer and be aware that the cure is not the goal of the care that is being provided.	-A qualitative approach use of the Interpretative Phenomenological Analysis method. -Use of in-depth interviews	Connectedness through spiritual beliefs -Shifting of hope took place when believed death is a possibility to prepare for the impending death -Reframing of the suffering experiences and meaning- making took place through understanding the - Spiritual and existential suffering Finding the purpose of suffering and meaning in life
Study 4 (Given in reference number 8)	16	-Parents who have a child diagnosed with cancer and receiving palliative care -Parents bereaving for three to 12 months	- a descriptive qualitative study using semi- structured interviews	- Received religious support - Pray to a higher power - comforting to pray - Religious acts help to cope - Pray to a higher power - comforting to pray - Believe in Supreme power
Study 5 (Given in reference number 24)	79	-Awareness of poor prognosis -physically well for participation	interpretative qualitative	-'Hope' achieved through spiritual faith -facilitated coping

		<ul style="list-style-type: none"> - Had children under 18 years of age - Resided in Northern Ireland - Experienced parental death to cancer - HSCPs who provide care to end-stage cancer patients - Funeral directors 		
Study 6 (Given in reference number 13)	13	<ul style="list-style-type: none"> -Above 18 -limited English proficiency -Family income equal to 200% of the federal poverty level -Have metastatic breast cancer 	-A qualitative study with semi-structured interviews	<ul style="list-style-type: none"> - The primary coping method was staying positive, - Believing that to survive cancer, the fighting is interconnected with hope - Ultimate decision is God's decision - Treatment providers and others are God's instruments for patient care and cure
Study 7 (Given in reference number 14)	12	<ul style="list-style-type: none"> - above 18 years - Kashmir citizens - Breast cancer diagnosis received 6 months earlier - ready to take part in the study- undergoing cancer treatment 	-Qualitative design using a phenomenological approach - Face-to-face in-depth interviews	<ul style="list-style-type: none"> -Religiosity and spirituality give support through <ul style="list-style-type: none"> - religious beliefs - religious practices - spiritual healers -Religious worshiping places such as shrines
Study 8 (Given in reference number 15)	19	<ul style="list-style-type: none"> -African American -men and women in the southeastern United States -age between 18 to 89 - have bereaved death of a loved one to cancer 	- Qualitative design with criterion sampling -semi-structured interviews - content analysis	<ul style="list-style-type: none"> - Participant engaged in the religious act before death - Inter and an intrapersonal connection - Motivating factor for the participant to live a decent life - need to develop a connection with God - God helps with the pain - Feelings of comfort when talk God - God is non-judgemental - death is a temporary state - God had the

				<ul style="list-style-type: none"> absolute power - God had limitless knowledge - God knows best
Study 9 (Given in reference number 16)	10	<ul style="list-style-type: none"> - English speaking - Above 18 - Experienced the loss of an immediate family member to a terminal illness 	-Cross-sectional qualitative design with the use of semi-structured interviews	<ul style="list-style-type: none"> -Religion and spirituality had a role in dealing with loss experiences as it was <ul style="list-style-type: none"> - Religion that gave comfort - Strengthens the individual when faced with difficult times -Gave different tools to cope
Study 10 (Given in reference number 20)	7	<ul style="list-style-type: none"> - Age between 12 – 20 -Had a sibling either - undergoing cancer treatment, completed treatment, or survived childhood cancer treatment, diagnosed between ages 0-16. 	-Qualitative explorative design with phenomenological and hermeneutic methods - semi-structured interviewing	<ul style="list-style-type: none"> -Having hope - Having faith <ul style="list-style-type: none"> - Praying to God helped to cope with the experience
Study 11 (Given in reference number 25)	31	<ul style="list-style-type: none"> -age 18 to 60 -No cognitive deficits -speak in Telugu. Kanada or English 	-Qualitative design -in-depth interviews -fieldnotes	<ul style="list-style-type: none"> - feelings of fear, sadness, nervousness, and worry - Belief in a higher power - believed that death is inevitable - Praying to a higher power to cope - Spending time with family and friends - Fulfilling daily wishes - Preparing for death helps to complete the unfinished business such as the marriage of children and writing up of the will
Study 12 (Given in reference number 1)	10	<ul style="list-style-type: none"> -confirmed recurrence of cancer -Jordanian -Free of Mental problem -Free of hearing problem 	Qualitative design -interpretative phenomenological approach -semi-structured interviews	<ul style="list-style-type: none"> Seeking complementary treatments such as spiritual activities <ul style="list-style-type: none"> - Involved in spiritual activities - praying, reading

				<ul style="list-style-type: none"> holy books, - and visiting holy places - helped to find meaning during illness experience -increased sense of control
Study 13 (Given in reference number 28)	29	<ul style="list-style-type: none"> -Parent studies had been conducted at the University Medical Center Hamburg-Eppendorf, Germany, in 2018 -Age 36 – 92 years -Had a family member diagnosed with terminal cancer 	secondary analysis (Heaton, 2004) of existing qualitative studies	<ul style="list-style-type: none"> - Faith in religion - The religious beliefs - Religious communities' traditions - Religious rituals - transcendence - Hope -Integration of spiritual experiences.