

## **Predictors of Anxiety, Sleep Disturbances and Somatic Symptoms among Caregivers of Cancer Patients: A Systematic Review**

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### **Abstract**

The present study is intended at reviewing the existing literature that reported the factors influencing anxiety, disturbances in sleep, and somatic symptoms among the caregivers of cancer patients, as well as the interventions to improve their wellbeing. Systematic review from Pub Med, Science Direct, and manual search from Google Scholar was done. Systematically reviewed articles on PubMed and Science Direct, from inception to 21st October 2020, to identify the studies that reported the predictors of anxiety, sleep disturbances, and somatic symptoms, and also the interventions that help to reduce these conditions, among the caregivers of cancer patients. Overall, 5932 articles were identified. 19 studies were finalized for the systematic review. Fifteen studies had discussed the predictors contributing to anxiety, sleep disturbances, or somatic symptoms, and four studies were related to the interventions intended to improve wellbeing by reducing the aforementioned clinical symptoms. Psychosocial factors including less emotional support from the care beneficiary and others, higher caregiving burden, less interaction and time for self, financial instability were found to be influencing anxiety, sleep disturbances and somatic symptoms. Music therapy, existential behavioral therapy, individual-based training interventions, and need-based interventions were reported to be applied with significant effectiveness.

*Keywords:* Anxiety, sleep disturbances, somatic symptoms, cancer caregivers

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Cancer is a disease with huge morbidity and fatality. The World Health Organization (WHO, 2020) labels cancer as the deadliest disease in the world and one among five people are diagnosed with cancer globally. It is a disease where its psychological effects can be seen in family members or caregivers of the patients too (Silveira et al., 2010). Everyday life may become very stressful for both the patient suffering from cancer and their family members'. The role of a caregiver for someone with a chronic condition can cause tremendous psychological burden (Hodges, Humphris & Macfarlane, 2005). Once the diagnosis of cancer is confirmed, family members begin grappling with challenges and start taking the role of a caregiver (Silveira, et al., 2010; Tamayo et al., 2010; Terakye, 2011). This stress can affect the treatment of the patient adversely and also the wellbeing of the patient. A meta analysis found that the relationship between psychological distress of cancer patients and their caregivers indicate that patients' distress affects the caregivers and at the same time the caregiver's distress also affects the patient (Hodges, Humphris & Macfarlane, 2005). The caregiver's depression and perceived burden dwindle the functional status of the patient (Grunfeld et al., 2004). So psychological dilemmas in cancer patients and caregivers are well-known and they are highly interrelated which can, in turn, have a subterranean effect on disease progression. Cancer patients always rely on their primary family and caregivers to deal with the malady and daily activities. Both patients and caregivers impersonate a joint struggle with cancer (Thomas, Morris & Harman, 2002). One meta-analysis on caregivers found that a higher level of behavioral problems in care recipients is related to the poor mental health of caregivers (Pinquart & Sorensen, 2007). Increased psychological issues in cancer patients are found to have resulted in a reduced chance of survival (Watson et al., 1999). Bambauer et al. (2006) had studied the reciprocal impact of the patient's psychiatric symptoms have a manifold manifestation on the caregiver.

There are many psychological issues diagnosed among cancer patients. Anxiety is stated to be a normal psychological response for those who care the cancer patients. However, this can interfere with their caregiving role and it requires more attention (Osse et al., 2006). Research conducted on the necessities of cancer caregivers reported that fear of unpredictable future was the predominant issue of caregivers while 48 percent of the caregivers experienced anxiety for their health (Osse, et al., 2006). Being family, caregivers are required to carry out added responsibilities for the patient and the family which will result in anxiety (Carey et al., 1991), and anxiety will result in other related psychological issues. Sleep disturbances, particularly insomnia, are prevailing among people with anxiety (Staner, 2003). Several studies have established an association between caregiver burden and sleep disturbance and that about 42% to 95% of cancer caregivers' experience poor sleep quality (Lee et al., 2015).

From the above literature, it is clear that most of the psychological difficulties of caregivers not only impact their wellbeing but also it adversely alters the condition of the patient too. Another regularly observed psychological condition in cancer patients is somatic symptoms. Somatic symptoms are persistent in cancer patients and a patient's condition can lead to somatic symptoms in caregivers. Common manifestations of somatic symptoms found were pain, fatigue, sensory, and mixed symptoms (Chaturvedi & Maguire, 1998). To provide proper physical and mental health conditions for cancer patients, their caregivers should also be in good health. Caregivers' psychological distress, depression, anxiety, and somatization will result in the poor psychological well-being of cancer patients and also a reduced probability of survival of cancer patients (Padmaja et al., 2016). There is also a consistent association of somatic symptoms with anxiety (Tyrer, 1976) as well as with depression (Katon, Kleinman, & Rosen, 1982). Polygamous family environment, conflicted marriage, poor social status, and socioeconomic constraints are correlates of somatization

(Obimakinda et al., 2015). Somatic symptom existence shows a higher risk or difficulty to manage work, home, carrying out leisure activities, and for maintain close relationships with others (Iheme et al., 2014).

Some of the common problems among caregivers of cancer patients are anxiety, sleep disturbances, and somatic symptoms. Anxiety can result in sleep disturbances (Staner, 2003), and at the same time anxiety results in somatization as well (Tyrer, 1976). Hence, anxiety, sleep disturbances, and somatic symptoms are seemed to be interrelated, and often co-morbid, with common predictors. At the same time, it is relevant to know about the interventions that help to reduce anxiety, sleep disturbances, or somatization. Somatization and somatic symptom presentation in caregivers and cancer patients are found to be neglected areas in the psychological health of both cancer patients and caregivers that require more researches to explore the proper therapeutic techniques for somatization (Grassi, Carsuo, & Nanni, 2013). This systematic review summarizes the existing literature that reported the predictors that contribute to anxiety, sleep disturbances, or somatic symptoms and interventions that help to reduce the same, among caregivers of cancer patients.

### **Methods**

The PRISMA guidelines were followed arranging the preferred reporting method and results for systematic review and meta-analysis (Moher et al., 2010).

#### ***Searches***

A systematic search was conducted on PubMed and Science Direct from inception to 21st October, (Fig. 1). A manual search was also performed on Google Scholar to identify additional relevant studies. The search keywords used were: "somatic symptoms" OR "somatic symptom" AND "anxiety" AND "sleep disturbances" OR "sleep disturbance" AND "cancer caregivers" OR "cancer caregiver".

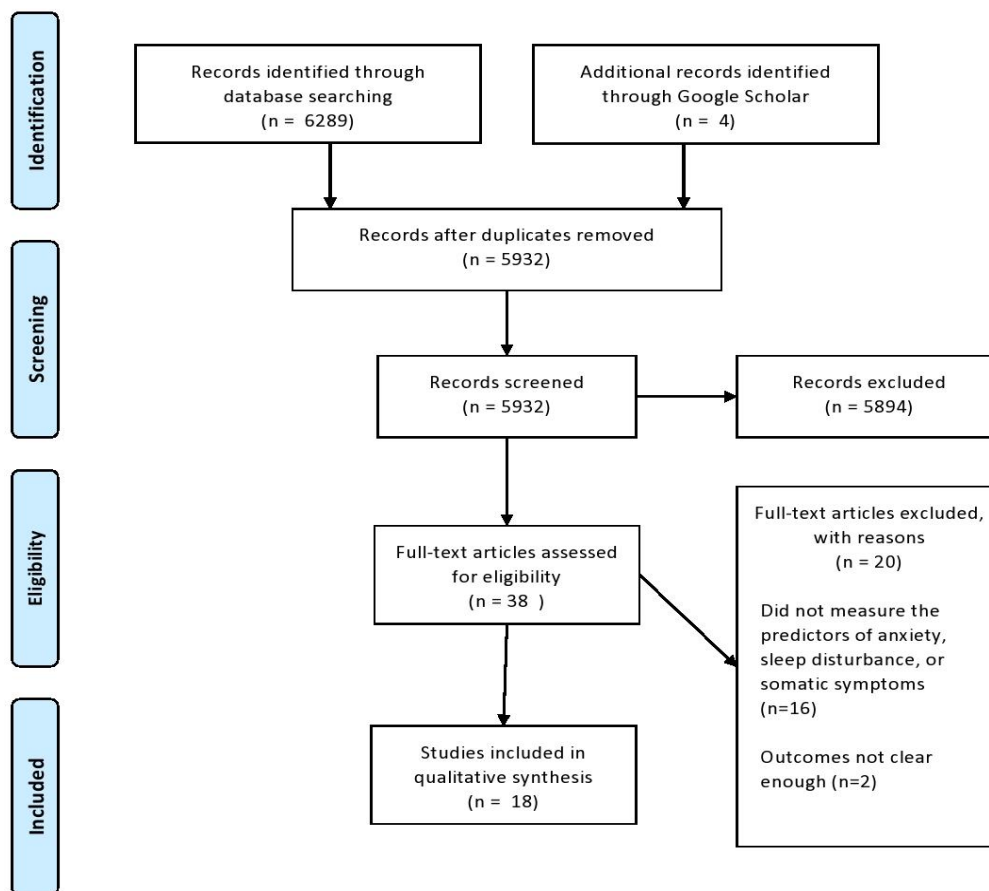
***Study selection criteria***

Studies followed an inclusion criterion based on: 1) if they were conducted on cancer caregivers, 2) if they studied the anxiety in cancer caregivers, 3) if they studied the sleep disturbances in cancer givers, 4) if they studied the somatic symptoms in cancer caregivers, 5) if there were intervention studies related to the anxiety, sleep disturbances and somatic symptoms among cancer caregivers. Studies were excluded if 1) they were in languages other than English. All titles and abstracts were thoroughly screened initially.

***Data extraction***

The relevant details included from the studies were 1) author and year of publication, 2) sample 3) age of participants, 4) predictors of anxiety, sleep disturbances, or somatic symptoms among caregivers, 5) type of intervention, 6) theoretical basis of intervention, 7) cancer type and 8) planned outcome of the intervention.

**Figure 1: PRISMA Flow Diagram**



**Results**

**Search results**

A total of 6293 studies were identified from which 38 full-text articles were selected in which 14 studies were excluded because they fail to measure the variables anxiety, sleep disturbances, or somatic symptoms; two were excluded where the outcome plan for intervention was not specific, and other four were excluded by reading the full text. 18 studies that met the inclusion criteria were selected for the final qualitative synthesis.

**Study characteristics**

The basic study findings and characteristics were given in table 1 and table 2. Amongst the 18 studies chosen, 14 were on the factors influencing anxiety, sleep disturbances, or somatic symptoms among caregivers of cancer patients, and four studies on

the different interventions done to improve anxiety, sleep disturbances, or somatic symptoms. Among the fourteen studies on factors, eight studies were conducted specifically among caregivers, and in the remaining six studies the samples were care-patient and caregiver pairs. Eight studies among fourteen studies had explored the factors influencing anxiety in cancer caregivers whereas three studies dealt with the predictors of sleep disturbances in caregivers specifically. One study examined predictors of both anxiety and sleep disturbances and one study dealt with factors influencing somatic symptoms among caregivers of cancer patients. In the case of four studies on interventions, one study was about the intervention for improving somatization and anxiety, two on improving anxiety, and one on improving both anxiety and poor sleep among caregivers of cancer patients.

### ***Predictors of anxiety among caregivers of cancer patients***

Nine studies out of eighteen studies have evaluated the factors affecting anxiety among caregivers of cancer patients (Sklenarova et al., 2015; Shin et al., 2018; Paek et al., 2018; Park et al., 2013; Price & Webb, 2010; Karabekiroğlu et al., 2018; García et al., 2020; Hou et al., 2016; Møller et al., 2020). The anxiety predictors were identified as inadequate support from family and workspace, suppression of anxiety in patients leading to increased anxiety in caregivers, the threat of losing the care recipient, less emotional dependence and underestimation of caregiver burden by care recipient, less sleep, financial concerns, reduced social support, caregivers' beings not well-informed of the patients' condition, low savoring, and detachment, and low social interaction. In most of the studies, the predictor mentioned was the caregiving burden, caregivers being not well-informed of the patients' condition, and also low social support.

**Table 1: Study characteristics on the predictors of anxiety, sleep disturbances and somatic symptoms**

Sl no	Author & year	Sample	Participant s' Age	Factors influencing anxiety, sleep disturbances, and somatic symptoms	Assessment tools used
1	Sklenarova, Krumpelmann, Haun, Friederich, Huber, Thomas & Hartmann, 2015.	Cancer caregivers and patients	Above 18 (caregivers)	Anxiety – less support from family, workspace. Suppression of anxiety in patients. The threat of losing.	Supportive Care Needs Survey for Partners & Caregivers. The National Comprehensive Cancer Network Distress Thermometer. Patient Health Questionnaire-4 (PHQ-4) quality of life (CQOLC-K; Korean version of the Caregiver Quality of Life IndexCancer), Depression and anxiety (Korean version of the Hospital Anxiety and Depression Scale Veterans RAND 12-item Health Survey (VR-12) physical component score (PCS). 10-item Center for Epidemiologic Studies Depression Scale (CESD-10). 7-item National Institutes of Health (NIH) Patient-Reported Outcomes Measurement Information System (PROMIS) Emotional Distress short form Anxiety 7a Korean Caregiver Quality of Life IndexCancer (CQOLC-K):
2	Shin, Lim, Shin, Kim, Yang, Chao & Park, 2018.	Cancer caregivers-patients	Above 18 (caregivers)	Anxiety – less emotional support from care recipient and underestimation of care giver burden by patients.	Fatigue Scale-14, trait Coping Style Questionnaire, and Symptom Checklist-90. Hospital Anxiety and Depression Scale,
3	Paek, Nightingale, Tooze, Milliron, Weaver &Sterba, 2018.	Care giver patients	Above 18 (caregivers)	Anxiety and sleep disturbances- higher caregiving burden, social dysfunction and less physical activity by care recipient.	Beck Depression Inventory (BDI), Beck Anxiety Inventory (BAI), Zarit Caregiver Burden Inventory and cognitive flexibility inventory Pittsburgh Sleep Quality Index
4	Park, Kim, Shin, Sanson-Fisher, Shin, Cho & Park, 2013.	Caregivers	Above 18	Anxiety- burden disturbance and financial concerns	Berlin Social Support Scale (BSSS), the Hospital Anxiety and Depression Scale (HADS)
5	Zhang, Yao, Yang & Zhou	Caregivers	Above 18	Sleep disturbances- higher financial burden, high mental and physical fatigue	Four back-translated items for psychological detachment and savouring . Twelve items were adapted from the Chinese version of The Zarit Burden Interview (ZBI) to assess cancer caregiving burden. The Chinese version of the 6-item state version of the State-Trait Anxiety Inventory. The Chinese version of the 21-item Beck Depression Inventory-II Cancer Caregiving Tasks, Consequences and Needs Questionnaire. Hospital Anxiety and Depression Scale (HADS)
6	Price, Butow, Costa, King, Aldridge, Fardell& Webb, 2010.	Patients and caregivers	Above 18 (caregivers)	Anxiety- lower social support lower optimism	
7	Karabekiroglu, Demir, Aker, Kocamanoğlu&Kar abulut, 2018.	Caregivers	Above 18	Anxiety- Cognitive flexibility level, Burden level and low social support	
8	Lee, Hsieh, Lin, & Lin, 2018.	Caregivers	Above 18	Sleep disturbances- high caregiving burden during daytime and more fatigued patients.	
9	García- Torres, JacekJabłoński, Gómez Solís, Moriana, Jaén- Moreno, Moreno- Díaz, &Aranda, 2020.	Caregivers	Above 18	Anxiety – less physical activity, more support seeking and less informational support received.	
10	Hou, Lau, Ng, Lee, Cheung, Shum, & Cheng, 2016.	Caregivers	Above 18	Anxiety –Savouring detachment and burden	
11	Moller, Jespersen, Lindahl-Jacobsen, &Ahrenfeldt, 2020.	Caregivers	Above 18	Anxiety- perceived information need about the disease for the caregivers	



12	Lee, Yiin, Lu, &Chao, 2015.	Caregivers	Above 20	Sleep disturbances- caregiving burden	Pittsburgh Sleep Quality Index (PSQI)
13	Harding, Epiphaniou, Hamilton, Bridger, Robinson, George, & Higginson,2012.	Caregivers	Above 18	Sleep disturbances- less emotional support for caregivers, less personal time and social interaction, financial issues, less information about patient's condition.	Nil
14	Padmaja, Vanlalhraaii, Rana, Nandinee, &Hariharan, 2016.	Caregivers and patients	Above 18 (caregivers)	Somatic symptoms- care recipient's anxiety, depression and distress	The Four- Dimensional Symptom Questionnaire (4DSQ)

### ***Predictors of sleep disturbances among caregivers of cancer patients***

The possible predictors of poor sleep in cancer caregivers were analyzed and described in the four studies among the eighteen reviewed articles (Zhang et al., 2014; Lee et al., 2018; Lee et al., 2015; Harding et al., 2012). Factors such as low emotional support for caregivers, less or no quality personal time for caregivers, financial issues, caregivers being less informed about the patients' condition, high caregiving burden, social dysfunction, low physical activity by the patient during day time, and high mental and physical fatigue were majorly contributed to the sleep disturbances of cancer patients' caregivers. Most of the predictors of sleep disturbances and anxiety were found to be highly related.

### ***Predictors of somatic symptoms among caregivers of cancer patients***

Somatization and somatic symptom presentation in cancer patients and caregivers are found to be neglected areas of psychological health of both parties (Grassi, Carsuo&Nanni,2013). Caregivers' psychological symptoms such as anxiety, depression, distress, and somatization was found to predict identical symptoms in cancer patients. Anxiety and depression in cancer patients contributed greatly in the somatic symptom presentation in caregivers of cancer patients (Padmaja et al., 2016).

**Table 2: Study characteristic related to intervention**

Author	Intervention	Theoretical base	Cancer type	Planned outcomes
Lai, Li, & Lee, 2012.	Music therapy	Psycho-physiological theory	Breast, Genitourinary, Gastrointestinal, head and neck, lung	Sleep Depression Anxiety
Mitchell, Girgis, Jiwa, Sibbritt, Burridge, & Senior, 2013.	Counselling based on needs.	Needs Assessment Tool-Carers (NAT-C) NAT-C-guided consultations	Advanced Cancer	Unmet needs Anxiety Depression Health-related quality of life.
Fegg, Kögler, Rechenberg- Fensterer, ... & Borasio, 2013.	Existential behavioral therapy.	Existential Behavioral Therapy(EBT)	Gynecological Lung Breast Brain	Somatization Anxiety Depression Life satisfaction Quality of life
Hendrix, Landerman, & Abernethy, 2013.	Paired intervention with nursing trainees	Nil	Nil	Primary outcomes: Self-efficacy on stress management and symptom management Preparedness Secondary outcome: Psychological well-being (Depression Anxiety)

### ***Interventions***

According to the literature reviews, several interventions were carried out to improve the quality of life in cancer caregivers. Among the 18 studies reviewed, four studies were on the interventions for cancer caregivers to reduce their anxiety, sleep disturbances, or somatic symptoms (Lai, Li, & Lee, 2012; Hendrix, Landerman, & Abernethy, 2013; Mitchell et al., 2013; Grunfeld et al., 2004). One intervention study to reduce anxiety among caregivers of cancer patients was done by applying music intervention (Lai, Li, & Lee, 2012). The music intervention in the form of record music presented in front of the nurse improved anxiety related issues and other psycho-physiological indices. The music interference with a nursing presence presented the listeners with a more affable music experience. Another intervention study by Hendrix, Landerman, & Abernethy (2013) was related to the individualized caregiver training intervention. The study tried to analyze the effect of individual training intervention on the psychological wellbeing of cancer patients by reducing the presence of anxiety and sleep disturbances. In this research, the self-efficacy of caregivers in-home

treatment and symptom control improved dramatically after receiving individualized caregiver instruction. But the psychological well-being enhancement in the area of anxiety, depression, and sleep disturbances was of medium effect. Yet another intervention study focused on the distinctly identifiable needs of caregivers of cancer patients (Mitchell et al., 2013). These special needs of people suffering from life-limiting conditions, and they should be given priority because if the caregivers are met with their needs they will be able to provide adequate support to the patient and at the same time they can be less anxious due to their caregiving burden (Mitchell et al, 2013). Individuals with pre existing conditions of anxiety and depression partially improved with this intervention, which is specially significant as people with terminal illness are found to have prevalence of anxiety and depression in one third to one half of caregivers of people with terminal illness (Grunfeld et al., 2004; Mitchell et al., 2014; Hauser & Kramer, 2004). Existential behavioral therapy was used in a study by Fegget et al. (2013) which helped to bring significant changes in reducing somatic symptoms and anxiety in caregivers of cancer patients.

### **Discussion**

Cancer is such a deadly disease that results in the decline of mental and physical functioning of both caregivers and patients. Caregiving is such an extensive and uneasy task where a person provides both their physical mental support to the other one in daily life. Treatment for loved ones with serious or extreme disease bears a heavy burden (Tamayo et al., 2010; Terakye, 2011). This stress will adversely influence the patient's recovery, mental and physical health, as well as the caregiver's (Terakye, 2011). Anxiety, sleep disturbances, and somatic symptoms in caregivers due to the distress of caregiving are the most relevant aspects of a caregiver's wellbeing (Fegg et al., 2013).

Anxiety is one frequent psychological response for those who care for patients with cancer. This conflicts with their role in providing treatment and it demands further effort. The

other related issue is sleep disturbance (Carey et al., 1991). Sleep disturbances such as insomnia are comorbid with anxiety disorders. Several articles suggest that between 42 to 95 percent of cancer caregivers suffer from sleep disorders and there is a link between the stress of treatment and sleep disorders (Carey et al., 1991; Staner, 2003). Somatic symptoms are the other dominant aspect in cancer patients and a patient's condition can influence the somatic symptoms in caregivers (Lee et al., 2015). From the literature, it is quite conceivable that the preponderance of the factors that influence anxiety, sleep disturbances, and somatic symptom presentation in cancer caregivers are psychosocial factors. The majority of the factors that contributed to anxiety and sleep disturbances in the cancer caregivers were low emotional, physical, and informational support from the social workspace, and family; the suppression of anxiety by cancer patients or care recipient; high feeling of caregiving burden by caregivers; and also an underestimation of caregiving burden by patients (Sklenarova, et al., 2015). The other major aspects or predictors contributing to psychological health decline in caregivers were, less sleep by both caregiver and patient, high financial concerns, detachment fear, less savoring, less time for self-relaxing, poor knowledge about the information on the patient's condition, and disease progression.

Low emotional support from the family, society, and from care recipients; and high caregiving burden play important roles in the occurrence of anxiety and sleep disturbances of cancer caregivers. The studies found that whenever the caregivers started feeling like they are not getting enough support from the family, society, and care recipient, and also when they started feeling caregiving as a burden, the anxiety level of caregivers started increasing (Sklenarova et al., 2015). Also, researches suggest that caregivers with a high feeling of burden and less support are more prone to anxiety (Shinet al., 2018). Underestimation of caregiving burden by care recipient and less information for caregivers concerning the patient's situation and disease contribution also contribute to high anxiety and sleep

disturbances in caregivers. The studies found that if the caregivers are less aware of the disease condition of the patient then that could contribute to high anxiety in caregivers rather than when caregivers know all those aspects (García et al., 2020). Financial concerns care giving burden feeling, and less financial support majorly contribute to sleep disturbances. Also, studies suggest that if caregivers are more anxious they are more likely to have sleep disturbances (Staner, 2003).

From the literature, it was quite clear that somatic symptom presentation in cancer caregivers was a very less studied research area (Grassi, Carsuo, & Nanni, 2013). The predictors of somatic symptoms in cancer caregivers were anxiety, depression in care recipients, and also those in caregivers (Padmaja et al., 2016). The other important finding from the literature was that there is an interconnection between the patient and caregiver– the patient's psychological aspects can affect the caregiver's mental states and vice versa. So, caregivers of cancer patients should be suitably managed and proper psychophysical interventions should be administered to make them healthy.

Four of the eighteen studies concentrated on multiple strategies that help to improve the well-being of caregivers by reducing the facets of sleep anxiety problems and somatic symptoms. One intervention research to decrease the level of anxiety in cancer patient caregivers was performed based on a musical intervention. All kinds of musical interventions with and without the support of nursing staff were found to be useful in managing the patient's psychological recovery. The findings provide evidence that nurses can aid the therapeutic use of music for the welfare of caregivers is a research-based nursing intervention (Lai, Li & Lee, 2012). The other intervention research referred to the individualized caregiver preparation intervention (Hendrix, Landerman, & Abernethy, 2013). The research sought to examine the outcomes of individual training interventions on the psychological well-being of cancer patients by reducing the presence of anxiety and sleep disturbances. In this study, the

self-efficacy of caregivers in-home therapy and symptom management increased significantly after gaining individualized caregiver guidance. But in the case of psychological well-being, the increase in anxiety, depression, and sleep problems was mild. Specific needs of the cancer givers was targeted in the next intervention research (Mitchell et al., 2013). The wishes of people living from life-limiting illnesses are easily identifiable and should be the primary concern. If the caregivers get satisfied with their personal needs, they would be able to provide the patient with sufficient treatment support and at the same time being less stressed about their burden of care. This intervention displayed limited developments for people with poor mental health such as already prevailing anxiety and depression. Existential behavioral therapy was used as a strategy in a study by Fegg et al. (2013). The therapy was conducted to reduce or see the changes in the stress, quality of life like reduction in somatic symptoms, anxiety in caregivers of cancer patients. Medium to large effects was seen on the anxiety and somatization level of caregivers by applying existential behavior therapy to caregivers of cancer patients. Fair to broad impacts has been shown on the anxiety and somatization level of caregivers when applying existential behavior therapy to cancer caregivers.

### **Limitations**

The study is that it had found only a limited number of articles that indicate the lack of thorough empirical researches in the area. The current systematic review consists of studies that are both qualitative and quantitative due to which it was impossible to carry out a meta-analysis. The study could include only three databases and the inclusion of more databases would yield more comprehensive data.

### **Conclusion**

From the literature on the predictors of anxiety, sleep disturbances, or somatic symptoms among caregivers of cancer patients it can be understood that the factors contributing to these aspects are primarily psychosocial. High caregiving burden, mental and

physical fatigue, low social and emotional support from care recipient and others, underestimation of caregiving burden, financial burden, less time for self are some of the common and most influencing aspects for anxiety and sleep disturbances. Somatic symptoms presented among caregivers as a result of high anxiety and depression among caregivers as well as the care recipient. Interventions that help in reducing anxiety sleep disturbances or somatic symptoms evaluated were musical intervention, existential behavior therapy, individual-based training interventions, and need-based interventions for caregivers. The interventions should be tailor-made depending upon the needs of the patient as well as the caregiver. So the application of a novel intervention that comprehensively focuses on most of these psychological disturbances can be more effective.

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