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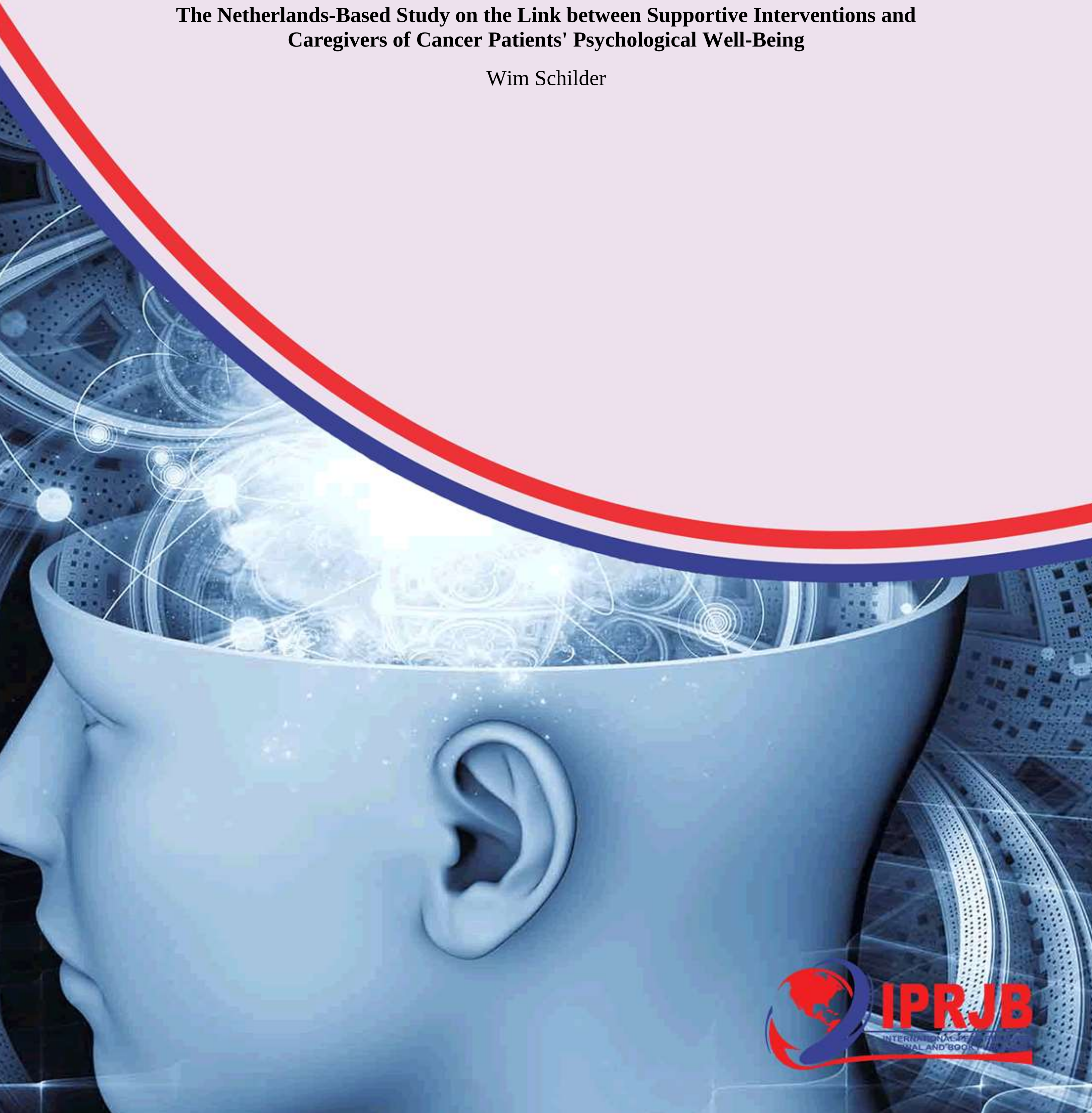

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Abstract

Purpose: The purpose of this study was to find out the link between counseling intervention and psychological wellbeing among care givers of cancer patients in Netherlands.

Methodology: The study adopted a desktop methodology. Desk research refers to secondary data or that which can be collected without fieldwork. Desk research is basically involved in collecting data from existing resources hence it is often considered a low-cost technique as compared to field research, as the main cost is involved in executive's time, telephone charges and directories. Thus, the study relied on already published studies, reports and statistics. This secondary data was easily accessed through the online journals and library.

Results: The results revealed that there exist conceptual and contextual gaps relating to the study on counseling intervention and psychological wellbeing among care givers of cancer patients in Netherlands. Preliminary empirical review reveals that provision of counseling and any social support was essential in enhancing psychological well- being of family care givers of cancer patients.

Unique Contribution to Theory, Practice and Policy: Family System Theory may be used in understanding the impact of terminal illness on the family. The results of this research may be instrumental in suggesting areas concerning counseling that are not effectively conducted with an aim of improving the counseling services in addressing the primary caregiver's needs in hospitals.

Keywords: *Cancer Patient, Caregiver, Counselling, Intervention, Psychological Well-Being.*

INTRODUCTION

According to World Health Organization (WHO, 2022) palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness? Cancer is causing 13% of all deaths worldwide, which is more than deaths caused by HIV/AIDs, TB and Malaria combined (WHO, 2022). A study that was done by Carpenter (2016) among 260 participants, established that cancer led to increased psychological anxiety and anguish. Cancer burden is expected to increase in Africa, due to aging and growth of population and prevalence of risk factors associated with economic transitions like physical inactivity and smoking (Jemal, Bray, Forman, O'Brien, Ferlay, Center, & Parkin, 2022). Globally, in 2022, 14 million new cases of cancer were reported while in Africa about 715,000 new cases of cancer were reported.

A family caregiver is a family member who is giving care to a patient. He could be the spouse, uncle, aunt or the parents of the ill person. In many communities, when a family member is ill, the relatives come together to provide care to their loved ones. Care giving has shifted from hospital and many patients prefer to be at home, hence, the care giving role has been left to the family of the patient (Grov, Dahl, Moum, & Fossa, 2015).

Caregivers have an important role in dealing with the needs of their loved ones who are terminally ill, starting from diagnosis, treatment and often times to death (Northouse, Katapodi, Song, Zhang, & Mood, 2020). Hudson & Aranda, Hayman, (2015) found that care giving brings positive outcomes despite its negative outcomes. Despite the family care givers knowing that they need to seek for professional help, they were reluctant as they prioritized the needs of the patients(Carolan, Smith, & Forbat, 2015).

A study that was done in America on objective burden, resources and other stressors on caregivers stated that one in four caregivers reported having low confidence in the quality of care they provided (Van Ryn, Sanders, Kahn, van Houtven, Griffin, Martin, & Rowland, 2021). Family caregivers have traditionally provided assistance with bathing, dressing, eating, and household tasks such as shopping and managing finances. While these remain critically important to the well-being of a care recipient, the role of family caregivers has dramatically expanded to include performing nursing tasks which were provided only in hospitals. Due to lack of professional training in nursing the patient at home feel disappointed and distressed especially when they find that they are unable to provide quality care (Reinhard, 2022).

In providing terminal care, the family care givers experience psychological effects but great emphasis is given to the patient by the palliative health workers. Family caregivers are often the sole caregivers to their loved ones; thus the physical, mental, and emotional well-being of the family caregiver impacts how they provide care. As events from one stage of life influence later stages, it is important to note that lack of appropriate and timely family support and resources can dramatically impact the life course of each family member (Reinhard (2022). A study that was done by Tunin and Uziely (2020) the family care givers were not able to provide quality care as they were not trained and lacked any professional support. A caregiver who lacks adequate resources and knowledge in caring for his or her loved one fails to be autonomous and not able to make any decision concerning the patient. Therefore, with psychological and emotional support, the family caregiver is able to master his environment as well as establish good relations with others (Bevan & Pecchioni, 2018).

Care giving can bring forth negative and positive effects on the caregivers. Positive effects are positive emotions and expression of love on the patient, while negative effects are psychological, physical and social issues which can lead to secondary stress in domains such as relationship issues, work and financial issues (Nijboer, et al., 2019). Caring for a cancer patient is a stressful event due to the chronic aspect of cancer especially from diagnosis, treatment procedures after diagnosis, and side effects of the disease as well as psychological effects of the anticipating death. A study by Northouse (2018) revealed that the patients and their caregivers have higher levels of psychological distress as compared to the general population and they did not differ much in their levels of distress. Care giving interferes with the caregiver's ability to engage himself or herself in activities like work, social outings and recreation. These disrupts the lifestyle of the caregiver which result to emotional distress(Cameron, et al.2022)**.** Caregivers are frustrated by not having useful health information to help their patients which make them feel inadequate in helping their loved ones as it leads to lack of sleep, and worry over the patient's well-being adding to caregiver's stress (Bevan & Pecchioni, 2018)**.** Psychological distress and morbidity have been demonstrated in informal caregivers of palliative patients. In addition, stress may be experienced by having to stand by and observe the disease progress as they are unable to change the situation of the illness (Carolan, Smith, & Forbat, 2015).

Psychological well-being is all about the life of an individual going well. It is a combination of functioning effectively as well as feeling good (Girum, 2022). A sustainable well-being does not require an individual to function well all the time. Feeling some pain at times is normal in life, and being able to overcome the negative effects is important for a long-term psychological wellbeing (Dzuka and Dalbert, 2020). However, psychological well-being is mostly compromised when extreme or long lasting emotions interfere with a person's ability to do his daily duties (Huppert, 2019). From this perspective, the psychological well-being of a family care giver is affected by the care giving role. At times, they are unable to speak or seek professional help when faced with negative emotions but rather keep quiet (Christine 2017). Therefore; there is a need to find out how the family care givers cope with their role as most of the time they are close to their loved one who is terminally ill.

Despite the psychological impact of caring, most caregivers do not seek help. According to Vanderwerker, et al., (2015) in his study with caregivers of cancer patients, almost half of the caregivers who met the diagnostic criteria of psychiatric condition did not seek help. Payne, Smith & Dean, (2019) asserted that for the caregivers to maintain their involvement in caring for the patient, they should be supported. That is why this current study aimed at finding out the relationship between counseling intervention and psychological well-being among family care givers of cancer patients in Netherlands.

Studies support that cancer affects patients as well as their significant others (Turner-Cobb, 2020). The family is gradually replacing the professional health worker in providing unfamiliar care to the ill person. The psychological processes which is essential in helping the care givers to maintain their sense of well-being is destabilized by their role burden. Therefore, it becomes difficult for them to be independent, have a positive relation with others as well as master their environment (Lent 2015). According to Given et al., (2021) if the family caregivers are informed and psychologically supported, they would have a positive psychological well-being. Despite, the evidence of the psychological effects of care giving on the family care giver, there is inadequate data on effective counseling interventions to curb these effects and do not seek counseling services as the needs of the patients comes first (Northouse et al., 2020), hence the current study set out to establish the relationship between counseling intervention and psychological well-being of family care givers.

Statement of the Problem

Families in Netherlands are facing worsening Cancer scenarios as it is ranked third in causing death. Cancer is the highest killer disease in Netherlands Country. Family care givers experience physical, psychological, social, spiritual and financial challenges once their loved ones are diagnosed with cancer and as they take care of them. Family care givers are expected to focus on the needs of the cancer patients, be available, and provide nursing tasks to them (Haley et al., 2015). Majority of the family care givers are not trained and prepared to carryout care giving role thus, leading to overstraining, helplessness as well as lack of opportunity to complain, therefore suffering silently (Ferrell, et al.,2018). Although the care giving role is stressful, some care givers cope well and tolerate the care giving burden. However, some find the care giving role to be emotionally challenging and they are unable to cope thus, being unable to provide quality care to their loved ones (Lambert, et al., 2015). Despite the studies indicating that counseling services help in mitigating the psychological distress of the family caregivers, there is scarcity of literature on counseling intervention among family care givers of cancer patients, and its relationship to recovery of their psychological well-being. Therefore, this prompted the need to find out the role that counseling intervention might play on the burden of care giving role among the family caregivers' psychological well-being in Netherlands

Theoretical Review

Family System Theory

Family system theory was developed by Bowen (1913-1990). Bowenian theory helped in understanding the impact of terminal illness on the family. A family is a system with interrelated elements, which show similar behaviors, regular interactions and are interdependent to one another. A change in one area of the system affects the rest of the system. Bowen views a family as emotional unit. In a family, the members are emotionally connected; they influence each other's thoughts, emotions, feeling and actions. The connection within the family provides each member with approval, support and attention from one another. Thus, within the system, if one family member has a problem, the whole family system is interfered. Most of the time disease management is done in a family. Every member of a family is aware that any disease especially cancer affects the whole family in various ways. These means, great value is not placed on the patient only but also to other members of the family. In a family where everybody is supporting each other and are free to express to one other, maintain a sense of connection and adapt to changes that affect the family (Aoun, 2015).

Terminal illness has significant and enduring effects on psychological, social and financial wellbeing of the family care givers. Family system theory specifies that a change in one part of the system affects the rest of the system. Some families have closed and rigid boundaries, while others have diffused and open boundaries. Families with rigid boundaries function in a nonadaptive and isolated manner. Families with diffuse boundaries have little identity, function chaotically and have little sense of connection with each other. Families that are able to support one another and allow each other to express their individuality are able to adapt to changes that affect the family system (Kristjanson & Aoun, 2015). When caring for a cancer patient, the family members should be incorporated in the treatment process. According to family system approach, cancer can be considered as an experience that brings the whole family together; every family member is interdependent on each other in coping with the illness (Gritti, 2022).

Family connection which is a tenet of family system emphasis that a family care givers, like a cancer patient need to be supported and cherished (Simpson & Rholes, 2015).The basis of the need to care for the family care givers is an attachment circuit that is In the brain of all human beings. Moreover, it motivates the desire for emotional support (Mikulincer &Shaver, 2017). The cancer patients who receive care giving from other family members that are empathetic as well as responsive to their needs; develop internal working models that enhance autonomy and positive relationship with others. With support and security comes optimism in one’s life. In addition, higher levels of care giving (closeness, caring and affection) leads to higher self-esteem, better psychological adjustment and more social competence. In a family characterized by negative family connection process leads to mistrust, rejection and neglect of the loved ones (George & Solomon, 2019).

Family individuation is important for the whole system to operate in a secure manner. The family care givers need to be nurtured and cherished. When the family care givers are emotionally supported, they become effective In their role as well as autonomous (Barber & Schluteman, 2018). An individuated family system that has interpersonal boundaries, the members think and speak for themselves, are encouraged, and are ready to accept other family member’s differences thus directing all their efforts towards mastering their environment as well as developing their capacity for an autonomous action (Coontz, 2015). In case of a negative individuation, there is no comfort, thus leading to a less accurate interpersonal perception. In this particular environment, it becomes difficult for the family care giver to become differentiated self or develop a sense of personal autonomy (Bell & Bell, 2019).

According to Bowen (2018) the main driving force for every family is the anxiety of balancing of the connectedness and separateness among the family members. In this perspective, the differentiation of self-guides the essential strategies that help in regulating the emotional distance of the family members. If the family caregiver is able to exert his own autonomy while caring for the cancer patient, then the family system is maintained (Kristjanson, & Aoun, 2015). The low ends of differentiation of self in a family lead to tension, emotional cut-off, triangulation and conflict between family members (Bowen, 2018). A study that was done by Krycak, Murdock & Marszalek, (2022), an individual who had lower levels of differentiation, experience higher levels of psychological distress as well as daily stress. Since differentiation is linked with psychological adjustment, self-control and well-being, it is essential to provide emotional support to a family care giver. From this perspective, differentiation of self should be maintained in order to improve the care givers relational well-being and better functioning in their role (Lampis, 2016). Therefore, through the family support and the provision of effective counseling intervention, a family care giver should not experience emotional cut-off and reactivity in providing their quality care (Wei, Vigel,Ku,& Zakalik, 2015).

Empirical Review

Kedia, Collins, Dillon, Akkus, Ward & Jackson (2020) investigated psychosocial interventions of informal caregivers of lung cancer patients. Caregivers of patients with lung cancer often face physical, emotional, and financial distress, which not only negatively affects the caregivers' mental health and quality of life but may also impact patients' well-being. The purpose of this systematic review was to examine the content, delivery, and efficacy of psychosocial interventions targeting caregivers of lung cancer patients. Studies included in this systematic review assessed psychosocial interventions for caregivers of lung cancer patients that were published in English between January 2009 and December 2017. These interventions focused on burden, mental health, quality of life, self-efficacy, and/or coping as outcome measures. CINAHL, PubMed, PsycInfo, Science Direct, and Web of Science databases were searched using the terms (lung cancer OR lung neoplasms OR thoracic cancer) AND (caregiver OR caregiving) AND (intervention OR program) to systematically review the relevant literature on this topic. The unmet needs of informal caregivers of lung cancer patients have a significant impact on their mental health and quality of life, but this burden can be alleviated by psychosocial interventions that offer appropriate support, education, and resources.

Kent & Dionne-Odom (2019) analyzed population-based profile of mental health and support service need among family caregivers of adults with cancer. The study examined associations between caregiving intensity and mental health among cancer caregivers at the population level and potential moderation by an actionable intervention target, support service needs. Behavioral Risk Factors Surveillance System survey data (2015) from caregivers of adult patients with cancer was analyzed. Caregiving intensity included hours per week caregiving (high, > 20; low, ≤ 20) and caregiving duration (long, > 2 years; short, ≤ 2 years). Mental health was reported as number of mentally unhealthy days (MUDs) in the past 30. Support service needs comprised caregiving classes, service access, support groups, counseling, and respite care. Multivariable linear regression models were performed adjusting for sociodemographic and sampling weights. The study revealed that High-intensity cancer caregiving was associated with poor mental health, especially for those reporting support service needs. Developing strategies to optimize support service provision for high-intensity cancer caregivers is warranted.

Lapid, Atherton, Kung, Sloan, Shahi, Clark & Rummans (2016) investigated caregiver quality of life. Caregiving can negatively impact well-being. Cancer caregivers face unique challenges given the intense nature of cancer and treatment, which increases their risk for burden, poor quality of life (QOL), and burnout. Studies to reduce caregiver burden demonstrate QOL improvement and distress reduction in the short term. However, few studies exist to address long-term benefits. We assessed changes in various QOL domains after participation in a QOL intervention for caregivers of patients having newly diagnosed advanced cancer. Institutional review board-approved study randomized patient–caregiver dyads to either usual care or an in-person group intervention composed of six 90-min sessions of structured multidisciplinary QOL components delivered over 4 weeks, with 10 follow-up phone calls within 20 weeks. Caregivers attended four of the six sessions attended by patients. Caregivers who received the intervention had higher QOL ratings for specific QOL domains but not for overall QOL. Although a comprehensive intervention was helpful, more specific, targeted interventions tailored for individual needs are recommended.

Mosher, Given & Ostroff (2015) investigated the barriers to mental health service use among distressed family caregivers of lung cancer patients. Although family caregivers of patients with lung and other cancers show high rates of psychological distress, they underuse mental health services. This qualitative study aimed to identify barriers to mental health service use among 21 distressed family caregivers of lung cancer patients. Caregivers had not received mental health services during the patient's initial months of care at a comprehensive cancer center in New York City. Thematic analysis of interview data was framed by Andersen's model of health service use and Corrigan's stigma theory. Results of the analysis expand Andersen's model by providing a description of need variables (e.g., psychiatric symptoms), enabling factors (e.g. finances), and psychosocial factors associated with caregivers' non-use of mental health services. Regarding psychosocial factors, caregivers expressed negative perceptions of mental health professionals and a desire for independent management of emotional concerns. Additionally, caregivers perceived a conflict between mental health service use and the caregiving role (e.g., prioritizing the patient's needs). Although caregivers denied stigma associated with service use, their anticipated negative self-perceptions if they were to use services suggest that stigma may have influenced their decision to not seek services. Findings suggest that interventions to improve caregivers' uptake of mental health services should address perceived barriers.

METHODOLOGY

The study adopted a desktop methodology. Desk research refers to secondary data or that which can be collected without fieldwork. Desk research is basically involved in collecting data from existing resources hence it is often considered a low-cost technique as compared to field research, as the main cost is involved in executive’s time, telephone charges and directories. Thus, the study relied on already published studies, reports and statistics. This secondary data was easily accessed through the online journals and library.

RESULTS

The results were grouped into various research gap categories namely as conceptual, contextual, and geographical.

Conceptual Gaps

Studies by Kedia, Collins, Dillon, Akkus, Ward & Jackson (2020), Kent & Dionne-Odom (2019), Lapid, Atherton, Kung, Sloan, Shahi, Clark & Rummans (2016), Mosher, Given & Ostroff (2015) had a conceptual framework gap. The link between counseling intervention and psychological wellbeing among care givers of cancer patients in Netherlands were not established by any of the research cited. The research did not provide a clear breakdown of the of counseling intervention and psychological wellbeing among care givers of cancer patients. Because of this, the current work aims to fill in these conceptual gaps.

Contextual and Geographical Gap

Studies by Kedia, Collins, Dillon, Akkus, Ward & Jackson (2020), Kent & Dionne-Odom (2019), Lapid, Atherton, Kung, Sloan, Shahi, Clark & Rummans (2016), Mosher, Given & Ostroff (2015) had geographical gap because they weren't actually done in Netherlands. This suggests that the findings may not be applicable in Netherlands due to the fact that the methods employed in each country vary. This study was undertaken with the intention of filling that void.

CONCLUSION AND RECOMMENDATIONS

The study may be instrumental in suggesting areas concerning counseling that are not effectively conducted with an aim of improving the counseling services in addressing the primary caregiver’s needs in hospitals in Netherlands. The findings of the study may also be useful to the Ministry of Health in ensuring that every hospice and palliative care unit has a professional palliative counselor.

The findings of the study were anticipated to be useful to the palliative counselors, health institutions, palliative care associations, hospice agencies, policymakers, and universities offering counseling courses, stakeholders in health, professional counselors, terminally ill patients and their families, researchers and curriculum planners in medical field. The findings and recommendations may help the policy makers to formulate proper policies related to counseling interventions in helping the family caregivers. The study may help the counselors to develop interest in researching for further information on how to deal with issues affecting family care givers. The study may add more knowledge which may be more useful to present and future scholars.

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