

Informal educational interventions for caregivers of adult cancer survivors

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Summary

This review study explores the available data relating to the informal education aspects of effective interventions applied in caregivers of adult cancer survivors to maintain their own health and quality of life (QoL) and as such to provide the optimal care to the cancer patient. The implications of these interventions in oncology practice are also discussed.

Available data show that, over the last years, a significant proportion of caregivers of cancer survivors are increasingly offered informal education interventions towards the reduction of their burden. More specifically, educational, skills training, and therapeutic counseling interventions seem

to positively affect caregivers' well-being and overall QoL.

However, based on available data, one cannot generalize these interventions on improving caregivers' outcomes of daily living activities and QoL. As such, available intervention strategies should be further tested and validated in larger samples, whereas novel health promotion educational approaches are expected to be designed to effectively address and comply with the appropriate needs of caregivers of cancer patients.

Key words: cancer survivors, caregivers, health promotion interventions, informal education, quality of life

Introduction

It is generally considered that a diagnosis of cancer results in immediate and long-term changes in several domains of life of both the patients and their families. As such, individuals with cancer and their family members are very likely to experience similar existential apprehensions and concerns as one emotional system [1]. This reciprocal effect is increasingly evident, because nowadays the role of caregivers has changed from relatively passive to active participation in decision-making. Moreover, treatment advances have led to a significant prolongation of survival of cancer patients and therefore caregivers are becoming all the more responsible for providing physical and emotional care to them over long periods of time [2].

Caregiver burden is a multidimensional response to various stressors associated with the caregiving experience. Available data advocate in favor of the view that caring for patients with cancer can be demanding and severely burdensome for their caregivers, who, not

uncommonly, they experience a similar degree of emotional distress and psychosocial problems like patients [3]. Several other factors, such as difficulties in communication between patients and caregivers and lack of appropriate information and education relating to the best possible way to cope with the disease-related challenges, may further decrease the ability of patients and caregivers to support one another, thus exerting a negative effect on the marital or family relationships [4,5].

The application of health promotion and informal education approaches onto oncology patients has recently attracted significant attention as literature contains studies prospectively evaluating lifestyle changes and other interventions to reduce cancer-related health risks in cancer survivors [6]. However, little is known relating to the most effective educational interventions for caregivers of cancer patients to ameliorate the well-being, the mental and physical health and their overall QoL.

To our knowledge, literature contains only few systematic reviews either solely describing the type, method and content of interventions applied in family

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caregivers of cancer patients or assessing in the same context their impact on multiple caregiver outcomes [7-11]. Available data show that interventions, such as psycho-educational approaches, skills training, and therapeutic counseling, seem to be largely effective in obtaining a positive impact on multiple outcomes of caregivers' well-being and overall QoL. The beneficial effect of such interventions appears to be real as the caregiving burden and emotional distress of caregivers have been reported as being decreased. On the other hand, self-efficacy, social functioning and benefit finding in the cancer caregiving experience are perceived as domains that should be improved. This positive effect has appeared to persist for a period up to 12 months or even longer in most of the aforementioned outcomes [11,12].

We herein review and discuss all available data relating to the informal education aspects and mostly effective interventions of caregivers of adult cancer survivors in order to maintain their own mental and physical health and QoL and, as such, to provide the optimal care to the cancer patient.

Interventions in caregivers of cancer survivors and effects on outcomes

Educational interventions

These interventions are perceived to be applied in both patients and caregivers, and primarily aim at providing information regarding psychosocial issues, such as stress and other physical symptoms management. Additionally, they explore the caregivers' emotional and psychosocial needs, communication and the impact of the disease on the marital and/or family relationships [13].

The majority of the interventions reported thus far are of educational type, being mostly applied in caregivers of breast and prostate cancer patients. In a randomized controlled trial (RCT), 36 caregivers of patients with breast cancer attended a brief educational group program, comprising 6 weekly sessions at clinical site lasting 1.5-2 hours. This program intended to help caregivers to manage patients' self care and marital issues. Analysis of results 3 months after the completion of the educational intervention showed that caregivers experienced less mood disturbance compared to controls, whereas greater marital satisfaction was reported from patients whose partners received the intervention [14].

In another setting with similar design, i.e. RCT, 89 patients with newly diagnosed cancer together with their corresponding caregivers attended an educational program combining joint meetings and telephone calls

of 20 minutes each. This program focused on symptoms' management, education on how to increase self-efficacy, emotional support, coordination of services and caregivers' preparation to care in order to diminish the depressive symptomatology of caregivers. An insignificant effect of the intervention on caregiver depression was observed. However, it has been found as being able to slow the rate of deterioration of depressive symptoms [15]. In another RCT assessing the efficacy of an educational intervention to family caregivers for caring issues of patients dying of cancer at home, it has been reported that, although the caregivers who received the intervention reported a significantly more positive caregiver experience than the controls, no beneficial effect was evident on issues relating to preparedness to care, self-efficacy, competence, and anxiety [16].

In a more recent study, a family-based intervention was applied to 235 dyads (prostate cancer patients and their spouses) to test the hypothesis that it could improve the appraisal variables, coping, symptom distress and QoL of the participants. The experimental group (n=112 couples) received standard care plus a 5-session family intervention. Caregivers reported an improved QoL and self-efficacy, better communication, whereas they also experienced less uncertainty, hopelessness and symptom distress compared with controls [17]. Finally, a recently published pilot study was conducted to test the ability of a new couple-based intervention program (6 biweekly joint sessions of 75 minutes) to manage the effects of breast cancer on the marital relationship of 14 couples. This approach has been shown as being able to improve the individual, medical, and relationship functioning of the participants [18].

Summarizing, although educational interventions appear to exert a beneficial effect on some aspects of QoL, i.e. they reduce the caregivers' burden and emotional distress, improve their coping abilities as well as the marital and family relationships, it is not clear whether they impact on the overall well-being and QoL of caregivers of cancer patients. As such, there is a need for further studies to prospectively assess the long-term efficacy of educational interventions in larger samples of patients and their corresponding primary caregivers. Further research is also needed to reveal the most suitable and effective educational intervention in caregivers of cancer survivors.

Skills training

Skills training interventions are those that primarily focus on the development of coping, communication, and problem-solving skills [19]. Available data show that skills training in caregivers of cancer patients

may substantially improve their QoL, reduce the burden associated with symptom management, and reinforce caregiving tasks [20].

Results of a RCT applying coping skills training (CST) interventions, i.e. 14 telephone-based sessions in a sample of 233 lung cancer patients and their caregivers, showed that caregivers experienced less anxiety and improved self-efficacy after the CST intervention [21]. Similarly, a partner-guided cancer pain management protocol was applied in 78 advanced cancer patients who were at the end of life and their caregivers. This approach consisted of a 3-session intervention conducted in patients' homes to provide integrated educational information about cognitive and behavioral pain coping skills. The results of this study have shown that a partner-guided pain management protocol may relieve cancer pain at the end of life, thereby reducing the caregivers' strain [22]. On the contrary, a clinical nursing intervention focusing on teaching family caregivers and their cancer patients' skills to better manage the patients' symptoms, and as such to reduce caregivers' depressive symptomatology, failed to decrease caregivers' depression [23].

Overall, it seems that the most effective skills training programs tend to be nursing intervention programs, which combine guidance, support, and nursing home visits. Nevertheless, we must point out that their application in oncology practice is limited and therefore we cannot generalize on their true value.

Therapeutic counseling

This type of approach is less frequently used in cancer settings. In any case, it has been designed to primarily focus on the development of a therapeutic relationship to address concerns related to cancer or caregiving. It also aims at helping patients diagnosed with cancer and caregivers to find meaning in their lives [24]. After the application of such intervention, caregivers of cancer patients were less distressed and reported lower levels of perceptions of underinvestment, over-benefit, and higher levels of relationship quality [25]. In another study, a family-focused grief therapy was applied in 257 families of patients dying of cancer to reduce distress of bereavement. The authors concluded that, although the overall impact of family-focused grief therapy was modest, it had the potential to prevent pathological grief [26]. In any case, disappointing results emerged from a previously published study in which a professionally provided program of social support counseling on newly diagnosed lung cancer patients and their families was offered for 6 months. In this study, all outcome measures of emotional, social, or physical function remained unchanged after the application of this

intervention. However, as the authors mentioned, there are several methodological issues which must be considered before any interpretation of these negative findings will be done [27].

Effects of interventions on specific outcomes

Self-efficacy

This outcome appears to be positively influenced by interventions at short or longer follow ups. Available data support the latter assumption as the majority of published studies report that interventions were superior to usual care both during the first 3 months after its completion and at longer periods ranging from 3 to 6 or even beyond 6 months [16,17,22,28].

Physical and social functioning

Informal educational interventions seem to favor the improvement of caregivers' physical functioning in a significant manner both between 3 to 6 and beyond 6 months of follow up [17,29]. Likewise, it appears that interventions are clearly superior over usual care in improving social functioning beyond 6 months after the completion of the applied intervention [26,29]. This effect appeared to be weaker between 3-6 months and rather poor at earlier follow up performed 1-3 months post-intervention [14,23,29].

Informational needs

Based on quite limited available data, thus hindering the interpretation and generalization of results, it seems that applying an informal educational intervention may positively affect the caregivers' appraisal of their informational needs just during the first 3 months after its completion [28].

Caregiving benefit

The effect of caregiving benefit appears to become significant at periods longer than 3 months as the majority of studies evaluating its effects during the first 3 months post-intervention reported a rather weak effect [18,25]. On the contrary, opposite results were evident from two studies, which assessed caregiving benefit between 3-12 months after the intervention [16,18]. Factors such as acknowledging what happened and appreciating new relationships with others were strongly related to greater benefit from caregiving and, as such, to improved adaptation [12].

Marital relationships

Available data show that the effect of interventions to improve marital relationships 1-3 months afterwards was significant [14,17,25]. However, this beneficial effect disappeared at periods between 3 to 6 months [18,26,27].

Depression and emotional distress

Depression was one of the factors that appeared to remain unaffected from specific interventions. Several studies assessed the longitudinal changes in caregivers' depression from the first 3 months up to periods longer than 6 months, and quite conflicting results were reported [14,15,17,22]. In any case, the overall effect size of interventions on depression at any time was estimated as being weak and insignificant [30]. However, this was not the case for emotional distress, for which relevant informal interventions were able to significantly reduce the levels of distress and anxiety for a period of up to 12 months [14,15,17,18,26,31].

Conclusion and future research perspectives

We herein have reviewed published data on informal education aspects and mostly relevant effective interventions to promote the personal health and QoL of caregivers of cancer survivors. Available data show that there are specific interventions, which hold promise for improving the physical well-being of caregivers. However, it is possible that interventions with multiple components, such as education about symptom management along with skill training in communication, managing roles and relationships and maintaining self-care, are more effective in improving the overall well-being and QoL of caregivers of patients with cancer. Single, individualized counseling interventions or a combination of them are mainly delivered to caregivers from oncology care providers, mainly nurses, together with the active participation of other trained personnel.

In any case, there are not enough data to conclude with confidence and support the effectiveness of any of these interventions. Factors such as the variability in the methodology applied among different studies, the mode of delivery and the type of intervention appear to mainly hold responsibility for the discrepancy between the reported results. Future informal educational interventions should be designed to assess the long-term effects and validate outcomes of these counseling processes aiming at the upgrading of the caregivers' QoL. Besides, early recognition of caregivers' elevated degree

of burden and distress is necessary in designing appropriate interventions and applying specific techniques.

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