

Web-based interventions for caregivers of cancer patients: A review of literatures

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ABSTRACT

Diagnosed with cancer is a traumatic event; it does not only affect the diagnosed patients, but also their caregivers. It brings along negative impacts on biopsychosocial health to the caregivers. Supportive interventions are essential for the caregivers to go through the cancer trajectory. In the past, interventions were being delivered in either face-to-face format or delivering written documents. Although Internet becomes a popular platform for delivering interventions given its substantial growth in usage, the effectiveness of this mode of intervention delivery is unclear. The aim of this review is to review existing literatures regarding efficacy of web-based interventions in psychological outcomes of cancer caregivers. A Literature search was performed in December 2012 from seven databases, including, Ovid MEDLINE, EMBASE, PsycINFO, CINAHL, ERIC, British Nursing Index and EBM Reviews. The following keywords were used in the search but were not limited to “paediatric”, “parent”, “caregiver”,

“cancer”, “web-based”, and “psycho education”. Totally 4668 citations were identified, after excluding the duplicated and irrelevant citations; finally six studies were included in this review. A review of the literatures identified that the web-based interventions including either online support group only or a combination of informational website and online support group significantly improved coping skills, in a way reduced anxiety, stress, depression, burden, as well as negative mood and perceived bonding in cancer caregivers. It is concluded that a web-based format as a potential platform for delivering intervention to the caregivers of cancer patients for its unique advantage of easy accessibility, and no geographic or time barriers.

Key words: Cancer caregivers, oncology, web-based intervention

Introduction

The incidence of cancer is increasing with cancer becoming a chronic disease, it does not only affect the patient but also devastates and traumatizes their caregivers, both patients and caregivers are facing substantial needs and problems.^[1,2] Taking care of cancer patients was challenging in which caregivers commonly experience caregiving burden. Their biopsychosocial health is

being negatively affected. Literature reviews found that caregivers experience physical problems such as fatigue, pain, and sleep problems. In addition to physical distress, caregivers suffered from psychological distress substantially. Psychological distress is defined as “the unique discomforting, emotional state experienced by an individual in response to a specific stressor or demand that results in harm”^[3] which is usually conceptualized as anxiety, depression, and mood disturbance.^[4,5] Care giving burden is found to be associated with anxiety and depression; about half of the caregivers suffer from anxiety and depression.^[6] Their levels of anxiety and depression were higher than the norm and even higher than the cancer patients.^[5,7] In social aspect, caregivers suffered from role strain and social isolation.^[4] As the caregivers play an important role in providing social and emotional support for the cancer patients and affect how well patients manage

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their health,^[8,9] supportive interventions are essential for these caregivers.

Studies reported caregivers considered knowledge and psychosocial support the common unmet needs,^[10-12] because low social support as well as caregiving burden induced stress and anxiety in caregivers,^[13] consequently the quality of care delivered was negatively affected.^[12] To fulfill these unmet needs, alleviate caregiving burden and facilitate coping, various non-pharmacology interventions such as psychoeducational intervention and support groups have been made available. Psycho educational intervention has been reported to improve the knowledge in disease information, such as cause, treatment and prognosis, stress coping and self care, care giving ability, and psychological distress of caregivers.^[5,13] Support group was also found to be a source of information that had positive impact on psychological health.^[14]

Traditionally, psychoeducational interventions are delivered in written and face-to-face formats. Information on diagnosis, treatment, and prognosis is usually delivered through pamphlets, articles, and fact sheets, whereas social support is delivered through face-to-face support groups.^[15] However, patients and caregivers are often reluctant to participate in health education and social support services because of the long travel times or uncomfortable feeling caused by embarrassment or feeling of stigmatization when participating face-to-face support group.^[16] Therefore, a convenient and effective platform for delivery support is needed. The substantial growth of the Internet has provided an optimal platform for supportive intervention; such a web-based approach has the unique advantages of interactivity, time efficiency, wide geographic reach, and anonymity.^[16] Thus, the web-based approach has become a popular means for intervention. The effectiveness of web-based interventions had been documented. Gustafson, *et al.*^[17] found that computer-based patient support system demonstrated a significantly greater increase in knowledge and improvement in social support. In addition, depression and stress level were significantly reduced with web-based interventions.^[18,19]

Despite the documented effectiveness and benefits of Internet there is a concern about the quality and accuracy of health information in the web.^[15] Also, there is an argument that web-based intervention lacked physical contact.^[16] Besides studies on the effectiveness of web-based interventions mainly focused on cancer patients, only few studies done in caregivers, thus the effects on caregivers was uncertain. There were different opinions

on the feasibility and applicability towards web-based interventions but little information regarding the effects and the limitations of web-based interventions in cancer caregivers, there is a need to address this gap. Thus, in this paper, the objective is to review existing literatures related to the efficacy of web-based interventions in psychological distress, social support, burden and coping of cancer caregivers.

Materials and methods

Search strategies

To review literatures on the effects of web-based interventions, search for literatures from inception until December 2012 was conducted. Relevant citations were search from the following bibliographic databases: Ovid MEDLINE, EMBASE, PsycINFO, CINHALL, ERIC, British Nursing Index and EBM Reviews. The keywords used in the search included but were not limited to “pediatric,” “child,” “parent,” “caregiver,” “cancer,” “oncology,” “web-based,” and “Internet”, “computer,” “psycho education,” “intervention,” “education,” “anxiety,” “depression,” “stress.”

Inclusion and exclusion criteria

Only articles written in English were included. Studies recruited caregivers aged 18 or older who were primary caregiver of patients diagnosed with cancer. However, studies focused on caregivers’ physical outcomes or focused on only patients or intervention providers’ outcomes were excluded. Non-experimental studies were also excluded in this review.

Results

Search results

Totally 4,668 citations were identified from the databases, among them 98 non-English citations were excluded. Another 355 citations were removed due to duplication. Titles of the remaining studies were being screened. Two hundred and eighty-six abstracts were reviewed after reading the article titles retrieved from the database. After excluding the irrelevant studies, 23 potential studies had their full papers obtained to check for eligibility; finally six studies were retrieved and included in this review. Hand searching through the references lists of all retrieved articles was performed and the studies were also examined [Figure 1].

Study characteristics

Among the six included studies, most of them were published between 2002 and 2012 ($n=6$) while one is in press. All the

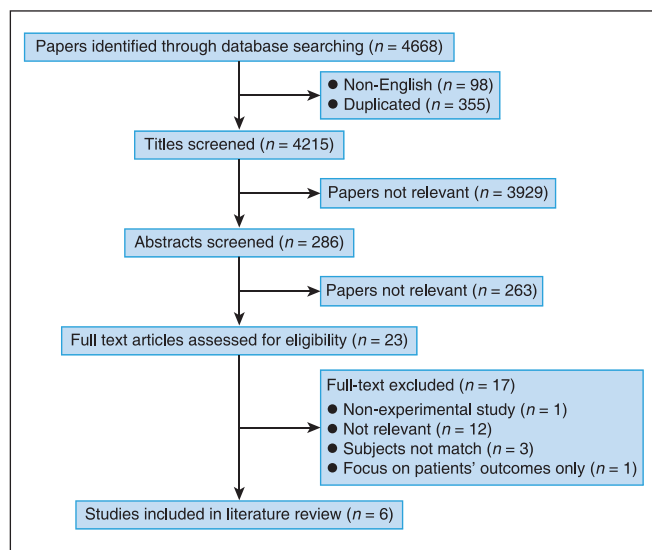


Figure 1: Flowchart illustrating the searching and selection procedures

six included studies were experimental studies. Three were randomized controlled trials (RCTs),^[20-22] one employed a mixed research method,^[23] the remaining two used quasi-experimental design^[24] and pre- and post-test design.^[25] Half of the studies (50%) were conducted in the United States ($n=3$); the others were done in Iceland ($n=2$) and Canada ($n=1$).

Three studies (50%) adopted theoretical or conceptual models ($n=3$),^[20,24,25] including the Transaction Model of Stress and Coping,^[20] the Calgary Family Intervention Model (CFIM)^[24] and the Flaskerud and Winslow's (1998) vulnerable population model.^[25] Three studies (50%) investigated the effects of web-based intervention in caregivers of paediatric cancer patients,^[23-25] while the remaining three (50%) were in caregivers of adult cancer patients.^[20-22] The characteristics and findings were summarized in Table 1.

Intervention characteristics

In terms of the intervention format, two studies focused on online support groups,^[23,25] whereas the other four studied the effects of the combination of an informational website and an online support group.^[20-22,24] In addition to the web-based components, face-to-face support interview was also included in one study as intervention.^[24] The duration of intervention ranged from 3 months to 2 years, with majority of the intervention lasted less than 6 months: 3 months ($n=2$), 4 months ($n=1$), 4-5 months ($n=1$).

Participants' characteristics

The sample size of the included studies ranged from 19 to 285 caregivers among the experimental studies. 50%

of the studies ($n=3$) examined the effects of web-based intervention on parents of cancer children,^[23-25] another 50% ($n=3$) done on caregivers of adult cancer patients.^[20-22]

Patients' characteristics

Majority of studies conducted in paediatric oncology comprised caregivers of children suffered from various types of cancers ($n=2$),^[24,25] the remaining was caregivers of brain tumor children ($n=1$).^[23] In contrast, all studies conducted in adult oncology, caregivers of were from homogeneous patient population, including lung cancer patients ($n=2$)^[20,22] and transplant patients ($n=1$).^[21]

Effectiveness of online support group for caregivers of cancer patients

Two studies examined the effects of online support groups.^[23,25] Bragadóttir investigated the effects of unstructured, professional-led online support group on 21 parents of children with cancer.^[25] In one group with pretest and posttest study, the participants were engaged in an online support group for 4 months. The levels of anxiety, stress, and depression were examined by using the Symptom Checklist-90 (SCL-90) and perceived stress scale (PSS), in which both instruments had good internal reliability. The levels of anxiety, stress, depression and somatization were examined. All the above outcomes, except somatization, were reported to have significantly decreased in the post-treatment of the parents: Anxiety ($P<0.01$), stress ($P<0.02$), and depression ($P<0.03$).^[25] This study also examined the effects of online support group on social support. The instrument adopted was the Perceived Mutual Support Scale (PMSS). The reliability of PMSS was not reported and the participants commented that many of the statements in PMSS scale were inapplicable. Nevertheless, it reported that parents indicated they perceived certain extent of mutual support in the online support group.

Another mixed method study by Nicholas *et al.*^[23] also included 21 fathers of children with brain tumor in the study. This study was initiated by a pretest-posttest phase followed by qualitative interviews. The fathers participated in a semi-structured, asynchronous, social worker led online support group for 3 months. Fathers' coping patterns and social support were measured by the Coping Health Inventory for Parents (CHIP) and Multi-dimensional Support Scale, respectively, both instruments possessed good internal reliability. Researchers reported that the coping skills of these fathers were enhanced. The fathers also expressed that the support group served as a platform for them to release and regulate their emotions. However, social support was insignificant to the participants.^[23]

Table 1: Summary of the included studies

Bibliographic data	Study design	Participants	Intervention	Control	Data collection time	Outcomes measures	Results	Strengths and weakness
Bragadottir, (2008) Country: Iceland	One group pretest and posttest design	Parents with cancer children ≤ 18 years who completed treatment within past 5 years before the study n=21 (11 mothers, 10 fathers)	Computer mediated support group (CMG) for consecutive 4 months n=21	None	Baseline, 2 months, 4 months after intervention	Anxiety Depression Stress Perceived mutual support	Anxiety level of fathers decreased significantly from T1 to T3 (mean score=0.36± 0.13, P<0.01) Depression of mothers was significantly improved from T2 to T3 (mean score=0.92 à 0.63, P<0.03) Stress was significantly decreased in fathers from T2 to T3 (mean score = 16.86→14.86, P<0.02) Perceived mutual support increased	Strengths: Research question, conceptual framework underpinning the study were explicitly explained. Instruments with high internal consistency used Weaknesses Reliability and validity of one instrument – Perceived Mutual Support Scale (PMSS) was questionable Small sample size High dropout rate No control group for comparison
DuBenske <i>et al.</i> , (in press) Country: U.S.	Randomized controlled trial	Caregivers of lung cancer patients who were English-speaking, with non-small cell lung cancer at stage IIIA, IIIB or IV, life expectancy of ≥ 4 months n=246	Comprehensive Health Enhancement Support System (CHES) website, a laptop computer with Internet access and usual care n= 124	Usual care and a laptop computer with Internet access n= 122	Baseline 2 months 4 months 6 months 8 months after intervention	Burden Negative mood	There was significantly lower levels in burden in intervention group (CHES: 12.97 Vs control: 16.37, P=0.021) at 6 months There was significantly lower levels in negative mood in intervention group (CHES: 0.56 Vs control: 0.92, P=0.006) at 6 months	Strengths: Randomization procedure was described High reliability of instruments were used Theoretical framework was adopted Patients' outcomes were assessed Adopted intention to treat analysis Weaknesses: High attrition rate Both control and experimental group were able to access internet
Farnham <i>et al</i> (2002) Country: United States	Randomized controlled trial	Aged ≥ 18, live up to 1 month in Hutch outpatient housing facility n=84 (35 patients, 49 caregivers)	Provide with computers with internet access and Hutch World	Not provide computer in their apartments	Baseline 28 days 56 days 84 days	Quality of life (social support, stress and life satisfaction)	There was no significant effect in quality of life Social support from family, friends and health care profession was significantly decreased in both groups (P<0.05)	Strengths: Study objectives and outcome variables were explicitly stated Weakness: Information regarding to the randomization procedure, allocation concealment, blinding were unknown The instrument used to measure quality of life was not mentioned. Dropout data was not presented. Due to high dropout, only the findings of first month were discussed. Long term effect of the interventions is not known. Low usage of the interventions
Namkoong <i>et al.</i> (2012). Country: U.S.	Randomized controlled trial	Caregivers of lung cancer patients who were English-speaking, with non-small cell lung cancer at stage IIIA, IIIB or IV, life expectancy of ≥ 4 months n=285	CHES website, a laptop computer with Internet access and usual care n= 141	Usual care, a laptop computer with Internet access n= 144	Baseline 6 months	Bonding Coping strategies	Perceived bonding was significantly improved in intervention group (P<0.05) There was no significant effect in the intervention group in coping strategies	Strengths: Hypothesis were clearly stated Instruments with high internal consistency used Weakness: High dropout rate Randomization procedure was unclear Not mention if follow intention to treat analysis Both control and experimental group were able to access internet

(Continued)

Table 1. Summary of the included studies (Continued)

Bibliographic data	Study design	Participants	Intervention	Control	Data collection time	Outcomes measures	Results	Strengths and weakness
Nicholas, Chahauer, Brownstone, Hetherington, McNeill, Boufflet (2012) Country: Canada	Mixed method: Quantitative Pretest and posttest of intervention, analysis of the forum postings and post intervention interviews	Fathers of children with brain tumor $n=21$	Closed online semi-structured, asynchronous, forum facilitated by trained facilitator for 3 months	None	Baseline Post-intervention	Paternal coping Social support	Father's coping was significantly improved There was no significant difference in social support	Strength: Instruments with high internal consistency used Weakness: Small sample size Sensitivity of instrument was questionable Dropout rate was not reported
Svavarsdottir, Sigurdardottir (2006) Country: Iceland	One group pretest-posttest quasi-experimental design	Parents with children and adolescents aged < 18, newly diagnosed with cancer; receive healthcare services in Landspítali University Hospital and able to speak Icelandic fluently $n=19$	Educational and informational website Support via internet 1 or 2 60-90 minutes support interview Duration: 4-5 months	None	Baseline 6 months 1 year	Use of coping strategies	There was no significant differences in the use of coping patterns in mothers	Strengths: Intervention was guided by theoretical framework Instruments with high internal consistency used Weakness: Lengthy self-reported items in instruments Small sample size Lack of control group

These two studies shared similar limitations:

1. They were all non-RCT studies, thus lack of a control for comparison and weaken the internal validity;
2. Sample size was small, ranged from 21 to 73.^[23,25]

In addition, other weaknesses include:

1. High dropout rate (29% to 38%)^[25];
2. Measurement instruments might not be sensitivity enough;^[23]
3. Included well-educated parents^[25] and homogeneous patient population^[23] which limited their external validity.

Effectiveness of the combination of informational website and online support group for caregivers of cancer patients

Four studies investigated the effects of the combination of an informational website and an online support group.^[20-22,24] In the RCT of Farnham, *et al.*,^[21] the quality of life of 84 cancer patients and their caregivers was assessed in terms of social support, life satisfaction, and stress. Both the experimental ($P<0.05$) and control groups ($P<0.05$) experienced a significant decrease in social support. No significant findings in life satisfaction and stress were revealed. On the other hand, DuBenske, *et al.*^[20] conducted another RCT to investigate the effects of the Comprehensive Health Enhancement Support System (CHESS) on quality of life in terms of burden and negative mood in 246 cancer caregivers. Burden were measures using the Caregiver Quality of Life-Cancer Scale (CQOLC) burden subscales, while negative mood was measured by Short Version Profile of Mood State (SV-POMS). All instruments adopted have demonstrated good internal reliability. CHESS intervention was a comprehensive web-based intervention offering information, discussion groups and coaching to the users. This study reported a significantly lower level of burden ($P=0.021$) and negative mood ($P=0.006$). Similarly, the RCT conducted by Namkoong, *et al.*^[22] examined perceived bonding and coping strategies in 285 cancer caregivers with CHESS. Perceived bonding and coping strategies were measured by bonding scale and Brief Cope, respectively. Both instruments reported to have good internal reliability. Perceived bonding of the caregivers was significantly and positively affected ($P<0.05$) but no significant effect on the coping strategies in the CHESS group. The fourth study included was conducted by Svavarsdottir and Sigurdardottir, it investigated the effects of website, online support group and face-to-face support interviews in 19 parents on coping. This study reported coping skill of parents was enhanced.^[24]

Regarding the strength of above RCTs, they adopted statistic tests to control the exogenous in data analysis;^[20,22] reported intention-to-treat analysis was used;^[20] reported the details of their randomization procedure explicitly.^[20] In addition, theoretical frameworks were used, which could facilitate the analysis and explanation of the mediating mechanism of the intervention.^[20,24] The common weaknesses of the above included RCT concerning the lack of details in randomization procedure, allocation concealment, and whether intention-to-treat analysis is used or not.^[21,22] Other limitations were:

1. No information on the instruments adopted, thus sensitivity of the instrument as well as the validity and reliability of the results might be questionable.^[21]
2. High attrition rate (26.7% to 57.7%) as the studies included advanced stage of lung cancer patients.^[20,22]

Discussion

This literature review showed the efficacy of web-based intervention on different outcomes. The web-based interventions, including both online support group only and combination of informational website and online support group significantly improved anxiety, stress, depression,^[25] coping skills,^[23,24] burden as well as negative mood^[20] and perceived bonding.^[22] Besides, the perceived bonding, which meant by information and emotional support was found to be significantly positively related to caregivers' coping strategies. With higher perceived bonding, the more active in behavioral coping and seeking instrumental support.^[22] Even though some of the outcome variables were found to be insignificant, such as adaptation and disruptiveness, it might possibly because of various methodological flaws, such as the lack of control for comparison, a small sample size and a high attrition rate. The limitation of small sample size and homogeneous sample, such as caregivers of a particular cancer or included only fathers, might limit the external validity, thus the finding might not be able to generalize to other study populations. Moreover, the majority of previous studies were conducted in single site; this might also limit the generalizability. In addition, two studies provided a laptop computer with Internet access to the control group, this might diluted the effect of interventions being examined.^[20,22] Another drawback of the studies was the omission of patients' outcomes, thus unable to examine whether improvement in caregivers' outcomes correlate to positive impact on patients' outcomes.

Due to the nature of web-based interventions, it is not feasible to blind the investigators and the participants to

types of interventions they received as this might contribute to information bias.^[26] However, none of the included studies had reported the blinding effort they had made, for example blinding to the data collector. Another limitation of the included studies is majority of these studies did not report the statistic power and whether or not they adopted intention-to-treat analysis, especially both RCT studies reported a substantial attrition rates. This would threaten the validity of the studies.

Despite the growth of web-based interventions, only few interventions were theory based; such theory based interventions can help to detect the causal relationship between the outcomes and intervention, as well as the mediating variables hence helps to generalize and explain the mechanism by which the interventions worked to affect the outcomes.

Moreover, the "dosage" of web-based intervention varied in the included studies. From the existing literatures, there is a wide variety of intervention time and no consensus on the effective dose of web-based interventions. Furthermore, few studies did measure the usage of the web-based interventions, however, they did not undertake measures to encourage engagement of the participants, for example sent email messages to those failed to access the interventions on a regular basis.

Conclusion

Web-based format is a potential platform for delivering interventions to the caregivers of cancer patients for its unique advantage of easy accessibility, no geographic and time barrier. This review found that web-based interventions could significantly improve the psychological distress, such as anxiety, stress, depression, negative mood and perceived bonding as well as enhance coping skills against stressors of the caregivers. Even though there is no conclusive evidence on existing studies, a comprehensive, theory-based, web-based intervention, which includes the combination of a website and an online support group, might be more beneficial to caregivers. Future research could examine the effect of such combined interventions. Besides, there is no consensus on the dosage of web-based interventions, the effective dosage of web-based interventions also worth to investigate in order to provide the most beneficial and cost effective intervention. In addition, the participants in existing literatures were limited to Caucasians and Westerners. The effects of web-based interventions specifically on the Asia population should thus be investigated.

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