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Family-oriented psychosocial intervention in children with cancer: A systematic review

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Abstract

Introduction: In recent years, evidence has shown the growing trend of published studies on family-oriented interventions in children with cancer. Besides shedding light on the current status of knowledge, a review of the existing evidence can serve an effective step toward designing and implementing appropriate interventions in this domain.

Methods: This systematic review was carried out to categorize and report the findings of all types of psychosocial interventions on the family caregivers of children with cancer. The English keywords "family career", "family caregiver", "children with cancer", "psychosocial", "intervention", "educational", and "childhood cancer" were searched in CINAHL, Web of Science (ISI), PsychINFO, Pubmed and Scopus databanks, and equivalent Persian keywords were searched in the SID of Jihad University, IRANDOC, and IranPsych and Magiran databanks. From among 819 papers found between 1994 and 2014, a total of 17 articles were included in the study after qualitative evaluation.

Results: Interventions were often performed on mothers and indicated various interventional approaches. The majority of the interventions were cognitive-behavioral which were reported to be effective in improving the measured criteria such as increasing the quality of life, decreasing emotional distress, anxiety and depression, and increasing adaptive behaviors.

Conclusion: The findings were generally reported to be hopeful and most of interventions were reported to have positive effects on the participants, among which behavioral-cognitive interventions were found to show the strongest evidence. Supportive interventions must be considered as an indispensable part of care for children with cancer.

Introduction

Among the childhood chronic diseases, cancer is of greater significance due to higher prevalence and greater impact on the life of the child and family (1). Cancer is the second leading cause of death in 1-14 year-old children (2). The petrifying nature of cancer imposes too much stress on the families of the children with cancer and challenges them to cope with various fears such as fear of death, fear of unknowns, and fear of disabilities and limitations. Further, the life-threatening diseases like cancer, due to affecting the patient and relatives, bring about numerous changes in the structure and performance of family (1). Psychosocial problems,

tension in parents' relations, social isolation, changes in career, family duties and recreational patterns, and lack of time to deal with healthy children have been proposed as other stressors in the families having children with cancer. The systemic attitude about family states that a change in a part of the family system affects the whole system and its internal relationship (3) and such changes not only affect the child but also influence the sisters, brothers, and parents (4).

Since the childhood cancers are among the life-threatening diseases (5), the role of parents as the primary and principal caregiver has been increasingly emphasized (6). Parents, especially the mothers of children with cancer are more exposed to psychological problems like anxiety, depression, stress, etc. than the

parents of healthy children (7). Increasing full improvement (79%) (8), tendency toward short-term hospitalization, and more reliance on outpatient care increase the pain of families in taking caring of the patients with chronic ailments (9, 10). Also, despite little knowledge about the consequences of diseases for families, the results of most of the studies show that the presence of a child with cancer reduces the life quality of the parents, especially the mother (11-14).

Based on the results of the studies conducted, because family is the first source of support and care for the patient (7) and that physical and mental health of the caregivers significantly affect the health, welfare and success of the patient and treatment process, familial support, as the main caregiver of the patient, is one of the most important healthcare policies in the domain of health. Thus, support interventions through various counseling methods, psychotherapy, and group interventions are an indispensable part of treatment for the patients with cancer and their families and should not be disregarded (15).

The family caregivers of children with cancer have rarely participated in intervention programs, most of which have been planned to improve the treatment results of the children and a few have directly targeted the needs of the family caregivers. However, the family caregivers of cancer patients have their own special psychosocial problems that need to be taken into account in order to maintain their health and to provide the best possible healthcare (16). Moreover, despite the numerous consequences of child cancer imposing on the family caregivers, most of whom are parents, few studies can be found to have investigated the psychosocial interventions on this group of caregivers or to have regularly reviewed the existing evidence in this regard (17). This is observable specifically in the analysis of the evidence presented by the domestic studies carried out on child cancer. However, a systematic review of these observations, in addition to explaining the status of the current knowledge, can be a step taken toward effective planning, implementing appropriate interventions and taking a beneficial measure to formulate the policies, guidelines and practical clinical instructions in this domain (18).

Although few studies have reviewed psychosocial interventions on child cancer, they have generally concentrated on the effects of these interventions on the children with cancer or the interventions performed with cooperation of family and child to evaluate their effect on the child. These reviews have mainly embarked on measurement of the effect of interventions on the child cancer, and no intervention has separately analyzed the family or parents as a principal caregiver of the child (17). Also, in the reviews conducted so far, one of the criteria of inclusion of studies for analysis has been the language of the published paper, which has mostly been English and the Persian studies investigating the effect of family-oriented interventions on the Iranian children with cancer have been excluded from analysis. Hence, the present study was aimed to assess, classify and

report the results of psychological, social and educational interventions carried out on the family caregivers of the children with cancer in order to more comprehensively review the domestic and international studies and achieve an overview of the current status of family-oriented interventions in this domain.

Materials and methods

This study is of descriptive type, and considering the study method, it is considered a systematic review. The study population of this systematic review consisted of all published qualitative studies regarding the interventions conducted on the family caregivers or the parents of the children with cancer during 1994-2014. First, the Persian keywords "psychological, social and educational interventions", "children with cancer", "parents of children with cancer" and "family caregivers" were searched in the SID of Jihad University, and IRANDOC, IranPsych and Magiran databanks, and English keywords "family career", "family caregiver", "children with cancer", "psychosocial", "intervention", "educational", and "childhood cancer" were searched in CINAHL, Web of Science (ISI), PsychINFO, Pubmed and Scopus databanks with different combinations. The manual search of the inventory of the related sources was also performed.

The studies were first analyzed according to title and abstract and irrelevant studies were excluded. Then, the articles in line with the study were included for analysis. Critical evaluation of the studies was performed by the qualitative evaluation checklist, Jadad score. Failure to meet the minimum qualitative criteria included lack of citing statistical methods, blinding, sample size calculation and randomized methods such as cases of failure to obtain a score by the given checklist. The family-based studies on the parents irrespective of the presence or absence of the child in the study, studies involving one of the controlled, experimental and quasi-experimental randomized clinical trials (with pretest and posttest), intervention on one of the parents, both of them or along with other family members of the patient like sister or brother, studies published in English or Persian, and studies involving one of different kinds of psychological, social and educational interventions were included in the study for analysis. The studies excluded from the analysis process comprised of those whose statistical society included the family caregivers of the adults with cancer or professional caregivers (treatment team) of the children with cancer, case studies providing only an intervention model without data evaluation, interventions performed on the caregivers at the end of their life and during bereavement, and studies published in other languages owing to high cost of translation. From 819 papers, after analysis of the titles and abstracts and exclusion of irrelevant and incompatible ones, 37 full text papers were subjected to critical assessment and a total of 17 papers were eventually chosen for analysis (Figure 1).

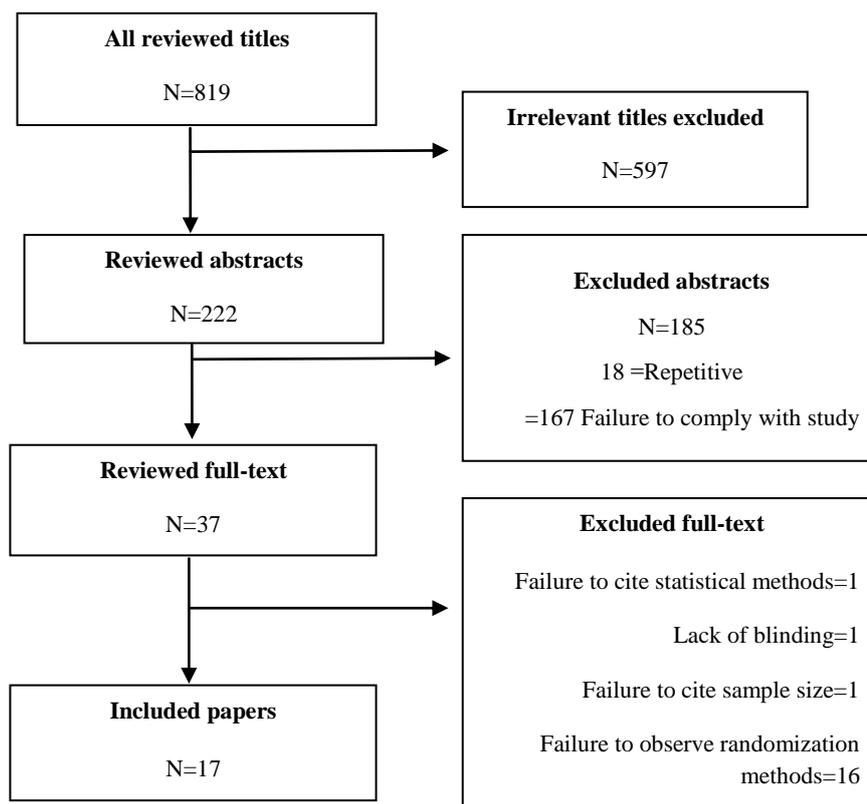


Figure 1. Flowchart of inclusion stages and selection of papers for systematic review

Results

To classify the papers included in the study, the main components of the study, including research design, intervention type, study population, study sample,

measurement tools, and results were extracted, the results of which are presented in [Table 1 for better understanding and easier analysis.](#)

Table 1. Summary of the interventions performed on the families of the children with cancer (family caregivers)

| Authors (year and country) | Intervention type | Study population | Research design | Study sample | Measurement tools | Major findings |
|--|---|--|---|----------------------------------|---|--|
| Bahman Bahmani et al. (2013, Iran) (19) | Existential psychotherapy (9 training sessions) | Parents of children with cancer at MAHAK hospital | Quasi-experimental | 30 parents (case=15, control=15) | 1. Beck Depression Inventory (1996) 2. Miller Hope Scale (1988) | Intervention significantly decreased depression and increased hope in experimental group ($p<0.01$) |
| Ziba Barghi Irani et al. (2012, Iran) (20) | Emotion-centered therapy (8 training sessions) | Mothers of children with cancer at Kermanshah health centers | Quasi-experimental | 30 mothers (case=15, control=15) | 1. Life Quality Scale 2. Enrich Marital Satisfaction Questionnaire | Intervention significantly increased the life quality and marital satisfaction of mothers ($p<0.001$) |
| Tahereh Hoseini Ghomi et al. (2009, Iran) (21) | Resilience training (9 training sessions) | Mothers of children with cancer at Imam Khomeini hospital, Tehran | Quasi-experimental | 30 mothers (case=15, control=15) | 1. Conner-Davidson Resilience Scale 2. Abidin Stress Test 3. World Health Organization Quality of Life (short form) | Resilience training intervention significantly reduced stress and increased the life quality of mothers ($p<0.01$) |
| Sedigheh Khanjari et al. (2012, Iran) (13) | Teaching coping skills (4 training sessions) | Parents of the children with cancer at two selected hospitals of Tehran University of Medical Sciences | Randomized controlled clinical trial (RCT) | 98 parents (case=48, control=50) | Persian version of Quality of Life Scale for the caregivers of patients with cancer | Educational intervention significantly increased the life quality of parents ($p<0.001$) |
| Farah Lotfi Kashani et al. (2012, Iran) (22, 23) | Spiritual intervention | Mothers of children with cancer at Imam Hosein Hospital, Tehran | Quasi-experimental (one-group) pretest, posttest) | 12 mothers | 1. World Health Organization Quality of life (short form) 2. Kessler Distress Inventory | Spiritual intervention significantly reduced distress and increased the life quality of mothers ($p<0.001$) |

| | | | | | | |
|--|---|--|---|---|---|---|
| Hoekstra-Weebers et al. (1998, Netherlands) (24) | Cognitive-behavioral intervention | Parents of children with cancer (25-53 years old) | Randomized controlled clinical trial (RCT) | Experimental group=20, control group=21 | 1. Goldberg's General Health Questionnaire 2. State-Trait Anxiety Inventory (STAI) 3. State Anxiety Inventory (SAI) 4. Social Support List Discrepancies (SSLD) 5. Impact of Events Scale (IES) | The analysis of STAI, SCL, IES and GHQ showed a better status for the intervention group but SSLD index showed no significant difference (p<0.05) |
| Kazak et al. (1998, USA) (25) | Behavioral and pharmaceutical interventions | Parents of children with cancer | Experimental with case and control groups | Intervention group=47 families, control group=70 families | 1. Methods Perception Scale 2. Parenting Stress Index-Short Form (PSI-SF) 3. Pediatric Oncology Quality of Life Scale (POQOLS) | Reduced stress between the case and control groups. The score of quality of life scale was higher in the case than in control group (p<0.001) |
| Kazak et al. (1999, USA) (26) | Cognitive-behavioral and family therapy intervention | Parents of children with cancer | One-group pretest, posttest (A pilot study) | 19 parents | 1. Posttraumatic stress disorder scale 2. Impact of Events Scale-Revised (IES-R) 3. State Anxiety Inventory (SAI) 4. Revised Children's Manifest Anxiety Scale (RCMAS) 5. Family Life Scale (FLS) 6. Program Evaluation Form | The results were positive for all scales but the family life scale showed no significant difference in all subscales (p<0.001) |
| Kazak et al. (2004, USA) (27) | Cognitive-behavioral intervention | Parents of children with cancer | Randomized Controlled Trial (RCT) | 150 families (300 parents in two case and control groups) | 1. Posttraumatic Stress Disorder 2. Impact of Events Scale-Revised (IES-R) 3. State Anxiety Inventory | Both family and children reported a significant reduction in indices 1, 2 and 3 after intervention compared to control group (p<0.05) |
| Kazak et al. (2005, USA) (28) | Surviving Cancer Competently Intervention Program-Newly Diagnosed (SCCIP-ND) (3 training sessions) | Parents of children with newly-diagnosed cancer at Philadelphia pediatric hospital | Randomized Controlled Trial (RCT) | 48 parents (case=18, control=20) | 1. Impact of Events Scale-Revised) 2. Acute Stress Disorder Scale (ASDS) 3. State Anxiety Index (SAI) | The intervention group was in a better status in indices 1-3 (p<0.001) |
| Sahler et al. (2002, USA) (29) | Problem Solving Skills Training Program (8 training sessions) | Mothers of children with newly-diagnosed cancer | Randomized Controlled Trial (A pilot study) | 92 mothers (case=???, control=???) | 1. Social Problem-solving Inventory-Revised (SPSI-R) 2. Profile of Mood States (PMOS) 3. Social Problem-Solving Inventory-Dysfunctional Problem Solving (SPSI-DPS) 4. Emotional Distress Scale | The mothers of case group reported lower emotional distress immediately and three months after intervention. The impact of social problem-solving skills training program was moderate (0.45-0.57) and that of dysfunctional problem solving was trivial (0.24-0.31). |
| Sahler et al. (2005, USA and Israel) (16) | Problem Solving Skills Training Program (8 training sessions) | Mothers of children with newly-diagnosed cancer | Randomized Controlled Trial (RCT) | 429 mothers (case=217, control=212) | 1. Problem Solving Inventory-Revised (PSI-R) 2. Profile of Mood States (PMOS) 3. Impact of Events Scale-Revised (IES-R) 4. Beck Depression Inventory-II (BDI-II) | The intervention group had a better status in indices 1-4 (p<0.001) |
| Svavarsdottir et al. (2006, Iceland) (30) | Internet-based educational and support intervention and one-on-two support interview focusing on treatment and management of diseases | Parents of children with cancer soon after diagnosis | Experimental (one-group pretest, posttest) | 19 families (parents) | 1. Comparative Fit Index (CFI) 2. Coping-Health Inventory for Parents (CHI P) 3. Family Hardiness Index (FHI) 4. General Well-being Schedule (GWB) 5. Family Adjustment Scale (FAS) | Parents reported a significant improvement in general well-being index, adaptive health, adaptive behaviors and family hardiness six months and one year after intervention (p<0.05) |
| Atehl et al. (2009, USA) (31) | Surviving Cancer Competently Intervention Program-Newly Diagnosed (SCCIP-ND) (3 training sessions) | Parents of children with cancer soon after diagnosis | Randomized Controlled Trial (RCT) | 82 families (intervention =42, control=40) | 1. Impact of Events Scale-Revised (IES-R) 2. Acute Stress Disorder Scale (ASDS) 3. Anxiety Test | No significant difference was found between intervention and control groups in the scores of scales 1-3 (p>0.001) |

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|-------------------------------------|--|---|-----------------------------------|---|--|---|
| Othman et al. (2009, Malaysia) (32) | Conventional standard care + four sessions of educational and psychological intervention on cancer information and adaptive strategies | Parents of children with cancer | Quasi-experimental | 79 parents (case=??, control=??) | 1. Knowledge assessment Scale 2. Anxiety Test 3. Strain Questionnaire 4. Strengths and Difficulties Questionnaire 5. Parents' Physical Activity (PA) with Children Scale | The parents of intervention group reported a rise in knowledge and a reduction in anxiety ($p<0.001$), but no significant difference was observed between the case and control groups in other scales ($p>0.05$) |
| Askins et al (2009, USA) (34) | Problem solving skills training plus personal digital assistant (PSST+PDA) for intervention group and problem solving skills training (PSST) for control group | English and Spanish mothers of children with newly-diagnosed cancer | Randomized Controlled Trial (RCT) | 197 mothers (case=93, control=104) | 1. Problem Solving Inventory-Revised (PSI-R) 2. Beck Depression Inventory-II (BDI-II) 3. Profile of Mood States (PMOS) 4. Impact of Events Scale-Revised (IES-R) | No significant difference was reported between conventional and computer-based interventions (both methods were effective). The results of both groups were found to be positive immediately and several months after intervention ($p<0.05$) |
| Fedel et al. (2012, USA) (34) | Cognitive-behavioral-based interdisciplinary intervention (12 training sessions) | Mothers of children with newly-diagnosed cancer | Randomized Controlled Trial (RCT) | 52 mothers (intervention =27, control=25) | 1. Symptom Checklist 90-Revised (SCL-90-R) 2. Behavioral Assessment for Children (2nd edition): Parent Rating Scale 3. Family Distress Scale | Significant results were reported for both groups immediately and several months after intervention ($p<0.05$) |

From among the 17 articles evaluated according to the study design cited in the main studies (Table 1), 9 articles were randomized controlled trial, 5 papers were pretest-posttest experimental and quasi-experimental and 3 cases were of one-group pretest-posttest experimental design.

Moreover, 8 studies were conducted at the healthcare and university centers of United States, 6 studies in Iran, 1 study in Netherlands, 1 in Iceland, 1 in Malaysia and 1 jointly in US and Palestine hospitals. In all the studies analyzed, intervention was carried out in the teaching hospitals, specialized pediatric cancer hospitals and pediatric department of the health centers. Also, 7 interventions were performed on the mothers of children with cancer, 7 on parents and 3 on the parents and children, either parents or children, or other family members.

The psychological, social and educational interventions analyzed in the present study included 9 cognitive-behavioral interventions (3 cases of problem solving skills training), 1 family treatment intervention, 3 interventions designed by interventionist and 1 case of resilience training, 1 emotion-centered treatment, 1 spiritual intervention and 1 case of coping skills training. Further, 2 interventions were performed by new methods of intervention and using such instruments as computer and internet.

In all studies, the measurements before and immediately after conducting the intervention were carried out on the experimental and control groups. During the follow-up, a posttest was performed between 1 and 12 months after intervention on the experimental group or a definite interval after pretest on the control group. This time was found to be different in various studies according to the intervention protocol.

The results of Khanjari showed that teaching coping skills was effective in enhancing the life quality and some of its dimensions, especially physical and mental

suffering, and lifestyle failure in the parents of children with leukemia (13).

Kashani concluded that spiritual intervention reduced the distress of mothers of children with cancer. In fact, spiritual intervention reduced psychological distress in both the patients with cancer and their caregivers. The results of this study also indicated that spiritual intervention promoted the life quality of the mothers of children with cancer. With regard to the impact of spiritual intervention on the life quality dimensions, the results of studies have shown that it significantly affects the mental well-being and social relations of the mother of children with cancer but it has no significant impact on the physical and environmental health (22, 23).

The results of Barghi Irani indicated that emotion-based training treatment increased the life quality indices in general health, physical performance, physical role, emotional role, social performance, mental health, and vitality dimensions. These findings show that the emotion-centered approach has the potential to, by increasing emotional knowledge, emotional notation, knowledge of involvement in experience and changing the processes, enable a person to control negative emotions such as anxiety, depression and despair and to reinforce psychological compatibility (20).

The results of Bahmani revealed that cognitive-existential therapy significantly reduced the mean depression and increased hope in the parents of children with cancer (19). Moreover, the results of the study by Hoseini Ghomi confirmed the effect of resilience training on reducing stress among the mothers and increasing their life quality (29).

Hoekstra-Weebers et al. concluded that cognitive-behavioral interventions improved the general health and anxiety of parents of children with cancer, but they reported no significant difference for social support before and after intervention (24). In their regular

behavioral-pharmaceutical, cognitive-behavioral, and surviving cancer competently interventions, Kazak et al. found that posttraumatic anxiety, stress, impact of events, anxiety and life quality indices were reported to be in a better position in experimental group than in control group (25-28).

Sahler et al. conducted a problem solving skills training program on the mothers of children with newly-diagnosed cancer and concluded that problem solving skills training improved emotional distress, impact of events, and depression indices (28, 16). Svavarsdottir et al. assessed the effect of internet-based educational and supportive intervention and support interviews focusing on disease management and treatment among the parents of children with cancer and reported a significant difference in personal well-being, family strength, and adjustment indices in intervention group (29).

The combined standard care and educational-psychological intervention performed in the study of Osman et al. led to reduced anxiety of the parents of children with cancer (32). The impact of event, depression, and problem solving skills indices in the study of Skinner et al. showed a better status in intervention group than in control group owing to the effect of PSST-PDA intervention (33). In their behavioral-cognitive intervention conducted on the mothers of children with cancer, Fedel et al. reported a significant reduction in emotional distress and depression indices (34).

As the results show, the outcomes of interventions concentrated on the family caregivers of children with cancer included instances like increased life quality, reduced emotional distress, reduced stress and anxiety, reduced depression, increased adaptive behaviors, increased family strength, changing problem solving methods, increased general well-being of family caregivers of children with cancer, and interventions mostly focused on the life quality of family members and improving their mood measurement results.

Discussion

Although psychosocial interventions are not performed extensively on the parents of children with cancer at clinical and health centers, especially in Iran, the existing information in this domain is acceptable for guiding the professionals working with them. The professionals such as psychologists, nurses and social workers make use of appropriate parameters and indices to measure the stress, anxiety, depression indicators and needs of the families of children with cancer in order to design a proper intervention (37).

The findings of most reviewed studies demonstrate that the majority of psychosocial and educational interventions carried out on the parents have shown the efficacy of intervention concentrated on the family caregivers of children with cancer (38). These interventions provide the parents with this possibility to clearly and freely express their feelings and experiences and to easily discuss their strategies in dealing with and adjusting to this issue and learn the techniques of adapting to conditions (39, 40). Also, the educational interventions performed on these caregivers have indicated a significant increase in their knowledge about diseases and their consequences as well as awareness of

financial and supportive resources that can be efficient for improving their conditions.

Studies have shown that combined psychosocial and educational interventions conducted to improve the mood and psychological conditions of caregivers and to inform them of the diseases and financial supportive and resources are more effective than single interventions (30, 32, 33). On the other hand, new intervention methods and tools such as computer and internet have been shown to have similar effects to those of conventional interventions (28, 30).

According to the analyzed studies, the interventions were often carried out at university healthcare centers and specialized pediatric cancer hospitals on the target population and were implemented as a part of family-centered pediatric therapy protocol, which guided the families in choosing how to participate in the treatment, how to receive appropriate and timely information, and how to cooperate with professional caregivers. Another dimension of family-centered intervention is that the health center and hospital are a friendly environment for the family, and freedom to run certain programs and proper physical conditions are considered factors contributing to family's participation in the treatment plan. In general, this result confirms the fact that attention to the university healthcare centers as the location of implementing intervention and training healthcare professionals and specialists is of great importance.

Moreover, since mother is the first sources of family support and care for the patient, supporting the patient's family and mother as the main caregivers has been proposed as one of the major health policies, and psychosocial and educational interventions are considered an indispensable part of treatment. Hence, the professionals need to get connected to the families of the children with cancer and design and implement proper psychosocial interventions to reduce the negative consequences of pediatric cancer diagnosis for parents (38).

With regard to the limitations of the studies reviewed, it can be argued that although most of the interventions have been carried out on the parents of children with newly-diagnosed cancer, they have not presented a clear and correct definition of this concept, except for two cases being defined from the time of diagnosis to two months after it (29, 30). In some of these studies, the number of samples is so limited that it is not possible to generalize the results to a larger community and the external validity of the study is under question (22, 23, 26). Furthermore, no study can be found to have investigated the efficacy of interventions on the caring load of parents, parental roles, and familial performance. However, the common lifestyle of parents and their roles will usually change due to the effect of childcare, thereby altering the performance of family for a short or long time (35, 36).

Despite presenting positive effects of interventions on improving the life quality and strength of families as well as the family life of children with cancer, this study was not able to provide sufficient evidence to show the effects of these interventions on other dimensions of family life like family performance, parental roles,

relationship with other children and social relations network, social support, and social participation of family. Therefore, it is necessary to perform studies to examine the effect of these interventions on the familial and social life of the family caregivers of these children and even to design intervention models in compliance with their social and familial needs. In addition, given the incongruity of studies in terms of the type of intervention, measurement tools, and implementation of intervention at different stages of diagnosis and treatment, only the characteristics of studies, their results, and differences and limitations were described and classified.

Conclusion

The overall objective of this study was presenting an overview of the current status of reviewing the studies associated with family-based psychosocial and educational interventions on child cancer with more comprehensiveness and inclusion of Iranian studies in the review process. The results indicated a growing

trend of studies published on family-based intervention on children's oncology and remarkable diversity of the performed interventions, including the use of different psychosocial and educational interventions, various combinations of parents and families, and presence of mothers as fixed participants in interventions. Considering the effectiveness of family-based interventions and improvement in the results of most of the studies, the findings were generally reported to be hopeful and most of interventions were reported to have positive effects on the participants, among which behavioral-cognitive interventions were found to show the strongest evidence.

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