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Effectiveness of a Brief Psychosocial Intervention on Quality of Life of Primary Caregivers of Iranian Children With Cancer: A Randomized Controlled Trial^{1,2}



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Background: Cancer in children has a great impact on primary caregiver quality of life (QOL).

Objective: This study examined the effectiveness of a brief psychosocial intervention (BPI) on QOL of Primary Caregivers of Children with Cancer (PCCCs).

Methods: Sixty-five PCCCs participated in a randomized controlled trial in Mahak Hospital and Rehabilitation Complex in Tehran, Iran. A 5-week long BPI (which comprised of counseling sessions and telephone follow-up) was delivered to the intervention group in addition to usual service, while the control group was provided with usual service. Data were collected using the Caregiver Quality of Life Index–Cancer–Persian version (CQOLC-P) prior to intervention, post-intervention, and at follow-up (i.e. 30 days after the intervention). Repeated measures analysis of variance analysis (ANOVA) was used to evaluate outcomes.

Results: Majority of the participants were mothers (95%), between ages of 24–47 years (95%) with children between ages of 2–12 years. Most child cancer diagnoses were for brain tumors ($n = 31$) and blood cancers ($n = 17$). Significant improvement was found within the intervention group on QOL ($p < 0.001$) including improvements on subscale measures of mental/emotional burden ($p < 0.001$), disruption ($p < 0.001$), and positive adaptation ($p < 0.001$), compared with the control group over time. There was no difference between the intervention and control groups on the financial subscale measure after intervention ($p > 0.05$).

Conclusion: BPI was an effective strategy to improve the quality of life of PCCCs. Similar interventions can be planned by practitioners to reduce the burden of childhood cancer on PCCCs.

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IN 2012, THE global burden of cancer rose to an estimated total of 14 million new cases per year, and it is expected to rise to a total of 22 million annually within the next two decades. Over the same period, cancer deaths are predicted to rise from an estimated 8.2 million annually to 13 million per year across

all age groups (WHO, 2014). Childhood cancer usually refers to all cancers occurring in children before 15 years of age. A worldwide estimated 175,300 new cancer cases occurred among children aged 0–14 in 2008 (American Cancer Society, 2011). According to a review by Mousavi, Pourfeizi, and Dastgiri (2010), the incidence rate of childhood cancer in Iran was 48 to 112 and 51 to 144 per million, among girls and boys respectively, in multi- geographical settings. Mousavi et al. (2010) also reported that the most common cancers in Iranian children from 0 to 14 years old are leukemia (8 to 62 per million), lymphoma (3 to 23 per million), and central nervous system tumors (3 to 22 per million). It was also reported that the rates of childhood cancer in Tehran (Iran's capital city) were higher than other provinces across the nation.

Primary Caregivers of Children with Cancer (PCCCs) take major responsibility for children with cancer. PCCCs are usually mothers of children or one of their family members. These individuals are at a higher risk for a variety of psychosocial problems such as depression (Creswell, Wisk, Litzelman, Allchin, & Witt, 2014; Sulkers et al., 2015), posttraumatic stress disorder (Shamsi, Azizzadeh Forouzi, Iranmanesh, & Dehghan, 2014), stress (Sulkers et al., 2015), economic difficulties (Miedema, Easley, Fortin, Hamilton, & Mathews, 2008), higher levels of family conflict (Pai et al., 2007), higher caregiving burden (Valizadeh, Joonbakhsh, & Pashae, 2014), and poorer quality of life compared with general population (Friðriksdóttir et al., 2011; Heidari Gorji et al., 2012; Klassen et al., 2008; Sajjadi et al., 2011; Song et al., 2011; Tamayo, Broxson, Munsell, & Cohen, 2010). Klassen et al. (2008) indicated that compared with population norms, parents of children with cancer reported poorer physical and psychosocial quality of life (QOL) in all psychosocial domains and in most physical health domains. Parent characteristics associated with better QOL included better eating, exercise and sleep habits, younger age, and higher income. It has been proposed that interventions directed at parents should be included as part of the treatment plan for a child with cancer.

According to the Pediatric Psychosocial Preventative Health Model (PPPHM) (Kazak, 2006), all families affected by childhood cancer will experience some distress and should have access to a universal level of support to build on their inherent resilience in order to enhance their ability to cope with childhood cancer. Some special interventions for child cancer patients and/or their caregivers have been developed and examined. For instance, Stehl et al. (2009) conducted three psychological sessions and three booster sessions for parents/caregivers of children with cancer shortly after diagnosis. Results showed no significant differences between the arms of the study on various psychosocial parameters. On the contrary, in another clinical trial, Marsland et al. (2013) reported that stress management intervention for primary caregivers of children newly diagnosed with cancer decreased participants' anxiety. There is also some evidence for the effectiveness of family-based interventions for children with cancer and their families (Meyler, Guerin, Kiernan, & Breatnach, 2010).

Interventions related to general distress and procedural pain in children with cancers have strong empirical support. According to studies, most survivors of childhood cancer and their families adjust quite well as they complete treatment; evidence-based interventions grounded in theory that can be implemented during and after treatment to address cancer-specific sequelae represent a vital and growing area of research (Kazak, 2005, 2006; Kazak et al., 2004). These interventions can be individual or combined interventions (e.g. training, education, counseling, support and family therapy) for the entire or part of the family of cancer patient. Most of these family-based interventions used family as a setting to reduce psychosocial consequences of childhood cancer on the patient and siblings (Wellisch, Crater, Wiley, Belin, & Weinstein, 2006; Wellisch et al., 2006; Williams et al., 2003; Windich-Biermeier, Sjoberg, Dale, Eshelman, & Guzzetta, 2007). Some of these interventions were conducted to improve well-being and quality of life for primary caregivers of children with cancer and were majorly parent focused (Kazak, 2006; Kazak et al., 2004, 2005; Khanjari, Seyedfatemi, Borji, & Haghani, 2013; Lotfi-Kashani, Vaziry, Arjmand, Mousavi, & Hashmyh, 2012a, 2012b; Svavarsdottir & Sigurdardottir, 2006). For example, Svavarsdottir and Sigurdardottir (2006) conducted a family-level intervention (including an educational and informational home page, support offered on the Internet to parents, and one or two 60- to 90-minute support interviews) for 10 families (19 parents) of children newly diagnosed with cancer and reported that parents' level of well-being increased significantly 1 month after the intervention. These results were also replicated in different parent focused interventions by Kazak and colleagues (Kazak, 2005, 2006; Kazak et al., 2004).

A few research studies have suggested effective interventions to improve PCCCs' quality of life in Iran. For example, Lotfi-Kashani et al. (2012a, 2012b) conducted six daily sessions of spiritual intervention for 12 mothers of children with cancer in Tehran and illustrated that spiritual interventions were effective in reducing distress and improving quality of life in mothers of children with cancer. Further, in a non-randomized clinical trial study in Tehran (48 cases and 50 controls), coping skills training was provided through four small group discussion sessions for parents of children with leukemia. The results showed significant increase in the overall quality of life for parents (Khanjari et al., 2013).

Conducting brief interventions increase the availability of support for PCCCs and they may be more willing to participate in interventions that take a short amount of time. Moreover, brief interventions have the potential to decrease the cost of services. Psychosocial support teams are in a unique position to identify and intervene with the PCCCs. Promoting the PCCCs' QOL is an important part of the role of psychosocial support teams in pediatric hospitals. They have an ongoing relationship with the PCCCs which enables them to develop rapport and provide services to improve QOL of PCCCs.

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