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Contribution of Benson's Relaxation Technique and Brief Psycho-Educational Intervention on Quality of Life of Primary Caregivers of Iranian Children with Chronic Diseases[1]

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ABSTRACT

Background: Chronic diseases leave a significant effect on not only the afflicted children but also their parents. Chronic diseases in children may also influence their parents' or primary caregivers' quality of life (QoL).
Objective: To determine the effectiveness of a Brief Psycho-educational Intervention (BPI) and Benson's Relaxation Technique (BRT) on the QoL of primary caregivers of children with chronic diseases.
Methods: The present quasi-experimental pre-test post-test design was conducted on 100 parents with children who had one chronic disease (50 in each of the control and intervention groups) and were admitted to two state-run pediatric hospitals in Tehran, Iran in 2014. The primary caregivers' QoL was assessed using the SF-36 questionnaire before (T1) and four weeks after the intervention (T2). The training was done in four 60–70 minute sessions over one week with a 4-week follow-up. Paired *t*-test, independent *t*-test, chi-square and Fisher's exact tests were used to analyze the data.
Results: On average, large effect sizes (ES ≥ 0.80) were observed after interventions in SF-36 subscales that measured the effect of emotional roles. Small (0.20–0.49) to moderate (0.50–0.79) ESs were found in subscales measuring physical functioning, physical-role, bodily pain, vitality, social functioning and mental health. General health scores remained relatively unchanged at T2.
Conclusion: These results suggested that BPI and BRT were effective strategies to improve the QoL of primary caregivers. Furthermore, interventions with low cost, and good safety and outcome could improve the QoL of primary caregivers of children with chronic diseases.

Introduction

Costly chronic diseases constitute some of the most widespread health problems in the world, claiming about 86% of health care costs (Center for Disease Control, 2016). Chronic diseases or non-communicable diseases kill 38 million people each year (WHO, 2015). The lifespan of children with chronic illnesses has increased in light of recent advancements in medical care and technology (Gibson, King, Kingsnorth, & McKeever, 2014). Children with a chronic condition rely on their primary caregivers for additional support and keep their health status in check (Ambikile & Outwater, 2012; Salvador, Crespo, Martins, Santos, & Canavarro, 2015). The trend of earlier discharge and outpatient treatment of chronic diseases entails that a child's family become more and more accountable for administering medication intake and managing the symptoms and side effects at home (Knafl et al., 2013).

Two highly prevalent chronic conditions in Iran are diabetes and chronic kidney diseases (CKD). Globally, 415 million people have diabetes, and >4.6 million people are reported to have diabetes in Iran in 2015 (International Diabetes Federation, 2015). CKD is another common chronic condition. It is believed that over an estimated number of 700, 000 people had CKD in Iran in 2004 and 61,000 new cases have been added since (Nafar et al., 2008). The condition is accompanied by enduring disability and complications, which impose high treatment costs on the patient, as well as disability-adjusted life years, in addition to the heightened risk of death (Nafar et al., 2008).

Primary caregivers of children with chronic diseases (PCCCDs) might have to deal with stress, disease burden, psychological strains, including depression, anxiety and fear, overwhelming guilt and uncertainty, loss of control, and dwindling positive adaptation (Cassidy & McLaughlin, 2015; Churchill, Villareale, Monaghan, Sharp, & Kieckhefer, 2010; Khanjari, Oskouie, & Langius-Eklof, 2012; Khanna,

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Prabhakaran, Patel, Ganjiwale, & Nimbalkar, 2015; Quittner et al., 2014). That is precisely why primary caregivers must get informed of the ways of managing their child's chronic disease, while helping their child to learn about the condition and its managing techniques. They also have to make medical decisions, prepare the ground to meet their child's needs in schools and health care settings, coordinate care, solve problems, continuously ensure emotional support, including planning and provision of daily meals, using medical equipment, and providing physical care such as attending to the wounds and lifting and turning (Churchill et al., 2010; Morawska, Calam, & Fraser, 2015; Tong, Lowe, Sainsbury, & Craig, 2010). Almost all aspects of a primary caregiver's life are affected when caring for a child with a chronic condition, including their own health status, mental well-being, economic and social activities as well as Quality of Life (QoL) (Fidika et al., 2015). Many family caregivers are of the notion that they don't have the essential skills and knowledge for providing long-term care for a person dealing with a chronic condition and hence lack confidence and feel incapable (Morawska et al., 2015; Smith, Cheater, & Bekker, 2015; Tong et al., 2010). As caregivers, parents require training on the existing and practical coping skills in order to boost their confidence as well as competence in providing care, which necessitates systematic education and support programs.

People use various coping strategies to go through difficult or stressful experiences. Primary caregivers need to be encouraged to use positive strategies to cope with difficult situations (Khanjari, Seyedfatemi, Borji, & Haghani, 2014; Tong et al., 2010). In order to increase the caregivers' strength to implement effective strategies (e.g. planning and active coping) intervention programs need to be developed and unaccommodating strategies (e.g. denial and self-blame) should be discarded (Yu, Hu, Efird, & McCoy, 2013). Familiarizing primary caregivers with specific coping skills such as self-empowerment, self-efficacy and essential relaxation techniques may prove effective in reducing depression symptoms and improving the coping abilities (Churchill et al., 2010; Khanjari et al., 2014). Improving the family caregivers' knowledge of effective and safe care-giving strategies, the measure could reduce or prevent their stress-born problems and improve their QoL (Fidika et al., 2015; Ji, Sun, Yi, & Tang, 2014). Thus educating parents about the child's illness and its management, parenting skills and coping strategies to deal with the stress of having a child with a chronic disease should be emphasized (Chi & Demiris, 2015; Tong et al., 2010). A growing body of research indicates that structured psychosocial interventions to teach coping and problem-solving skills can be a great benefit to the family caregivers (Stahl et al., 2015).

A practical and cost-effective method for challenging the psychological problems is practicing relaxation techniques that need no special equipment, and can easily be exercised by caregivers (Stahl et al., 2015). A number of studies have evaluated the effect of relaxation techniques on the QoL of people (Mizrahi et al., 2012; Masoudi et al., 2011; Akmeşe & Oran, 2014). In one study, the effect of a progressive muscle relaxation program on QoL among caregivers of patients with multiple sclerosis was evaluated in Iran (Masoudi et al., 2011). Another study in Iran investigated the effect of psychoeducational training on the QoL of family caregivers of patients with spinal cord injury (Molazem, Falahati, Jahanbin, Jafari, & Ghadakpour, 2014).

However, only a few research studies have shown that effective intervention improves QoL for PCCCDs. The purpose of this study was to evaluate the effectiveness of a Brief Psychoeducational Intervention (BPI) and Benson's Relaxation Technique (BRT) on the QoL of primary caregivers of children suffering from chronic diseases.

Methods

Design

This quasi-experimental pre-test post-test design was conducted between October 2014 and May 2015. The participants included 100 primary caregivers of children with chronic diseases (50 in each of the control and intervention groups). The participants in the intervention group and control group were selected from the medical wards of two different state-run pediatric hospitals in Tehran. The control group received usual services, including counseling, while the intervention group underwent a BPI and BRT in addition to the usual service. The 36-Item Short Form Health Survey (SF-36) Persian version was used for both groups before participation in the study to analyze the basic data (Time 1; T1), and four weeks after the intervention (Time 2; T2) to measure the PCCCDs' QoL. Sample size was determined at a confidence level of 95% and power of 80% and moderate effect size; a sample size of 50 for each group was deemed adequate.

Participants

Tehran has three public hospitals for children. Each is supervised by one of the city's medical universities. Two out of the three hospitals were chosen based on availability and the short distance between them. One of them was randomly chosen to be in the intervention group and the other was the control group. In each hospital, an invitation letter directed to these PCCCDs was posted on the walls, together with the inclusion criteria listed below.

The inclusion criteria for the children were (1) age 1–16 years old, and (2) having primary caregivers who were blood relatives. The inclusion criteria for the primary caregivers were (1) age over 18 years old, (2) literacy of Persian language, (3) not having a history of or current psychiatric or neuropsychological disorders, (4) not having chronic kidney disease or diabetes, and (5) having taken care of their child for at least one year. The exclusion criteria of the study included one child who was deceased, (2) the subjects' unwillingness to participate in or missing two sessions during their training course, (3) having experienced a significant life event unrelated to their child's condition in the past 30 days such as divorce, financial crisis, or death of a family member.

Out of the total 143 primary caregivers who completed the questionnaire at the pretest stage, 43 primary caregivers did not participate in the second phase (T2). The long home-to-hospital distance and commute was the most cited cause for missing the sessions. Furthermore, two more participants were excluded from the study, one due to pregnancy and unsuitable physical condition and the other because of the child's death (Fig. 1). These two participants were in the intervention group, and were excluded from the study for the above-mentioned reasons after completion of the first phase questionnaire and participating in four sessions. They did not complete the second questionnaire.

This study was approved by the Ethics Committee of Iran University of Medical Sciences (grant no. 93-D-105-2440) and the researchers abided by the Helsinki Declaration. The primary caregivers of all the children provided informed verbal and written consent. The information letter contained the purpose of the study and stressed confidentiality of the collected data, volunteerism and the possibility of withdrawal at any point during the trial. Moreover, the information letter included the name of the university where the research was going to be carried out. PCCCDs in the control group also received the educational package after the final intervention conclusion.

Intervention

The intervention comprised of BPI and BRT programs was designed to help improve the QoL of PCCCDs during all phases of their children's illness. The participants in the intervention group were trained by a pediatric nurse and a rehabilitation counselor. The number of participants in each session varied from three to six parents. Four sessions of training were held over four consecutive days during the week. The process continued until the size of the intervention group reached 50.

Each session was divided almost equally into three parts, consisting of lectures, group discussions and relaxation techniques, respectively. At