Kawakami et al. J Nephrol Ther 2016, 6:1
DOI: 10.4172/2161-0959.1000232

Journal of Nephrology & Therapeutics

Research Article Open Access

Application of Meditation Techniques in Caregivers of Children and Adolescents with Chronic Kidney Disease on Hemodialysis Therapy

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Abstract

Over the past 40 years, practice of meditation has increased considerably in the West, and has been used as a complementary therapy for a variety of diseases. Today, it is the third most commonly used complementary alternative therapy in American children and adults. Several studies have shown its beneficial effect on conditions such as depression, anxiety, panic attacks, eating disorders, post-traumatic stress, hypertension and cardiovascular disease. Stress affects the quality of life, not only in patients with chronic kidney disease (CKD) on hemodialysis, but also on their caregivers. A growing number of CKD patients depend on non-professional health caregivers, such as family and friends. However, the needs of caregivers are often neglected and under-prioritized. Considering the heavy burden caregivers of patients with chronic disease need to carry and the lack of intervention studies, the purpose of this study was to evaluate the benefits of the practice of meditation on the level of anxiety and depression in caregivers of children with CKD undergoing hemodialysis.

Keywords: CKD; Hemodialysis; Children

Introduction

The diagnosis of a chronic condition that affects the life of a child is extremely traumatic for the patient and the caregiver, particularly for the mother. It results in difficulty ofto cope with stress, a financial burden, absence from work and concomitantly, overprotection of the patient, due to his/her physical limitations, fatigue, fear of becoming different to their peers, school absences and undergoing painful medical procedures. All this affects the physical, mental and emotional development of the children, interfering with the dynamics of childhood and resulting in the deterioration in family relationships, and consequent imbalances in social and emotional behavior [1-3]. Quality of life (QOL) of chronically ill children and their families is therefore closely related and dependent on the parents' perception of their psychosocial situation and their reaction to it [3-5].

The more prevalent conditions in caregivers of patients with chronic disease are: anxiety, depression, drug abuse, reduced quality of life and higher mortality rate [6-8]. The identification of these conditions through an early monitoring of their strain, and the application of methods that can be beneficial to both the patients and caregivers, can improve their state ofwell-being.

Most studies evaluating QOL are focused on population of caregivers of elderly patients or adults with chronic illness. A family caregiver is defined as a relative or friend who provides unpaid care for people with chronic or disabling conditions. The introduction of family caregivers in the US health care system resulted in lower hospital occupancy rates and reduced costs compared with hospital treatment [9], with studies showing a 44% reduction in total spending costs [10]. But despite the benefit of cost-effective relation, this trend transfers more financial, physical and emotional responsibility to the family members who have fostered a chronically ill patient [11].

On the other hand, there is little information regarding the level of stress on parents of children with chronic diseases. A study showed that they are twice as likely to show symptoms ofdepression, chronic diseases and activity limitation compared to the population caregivers of healthy children [12]. On the other hand, there are few intervention studies on this population, and the most offered solution is information about the disease and how to approach the symptoms.

Over the past 40 years, the practice of meditation has increased considerably in the West, and has been used as a complementary therapy for a variety of diseases. Meditation was the first of the mind-body interventions to be adopted in healthcare and is currently the third most commonly used complementary alternative therapy in American children and adults [13]. The alternative or complementary therapies most commonly used in American adults over the past 12 months were: the use of non-vitaminic and non-mineral natural products (17.7%), deep breathing exercises (12.7%), meditation (9.4%), chiropractic or osteopathic manipulation (8.6%), massage (8.3%), and yoga (6.1%) 13.

The diversity of the definitions of meditation reflects the complex nature of its practice and Cardoso et al., presented an operational definition of meditation that involves a wide concept, enough so to include traditional practices and those that have been specifically developed for medical practice [14].

Several studies have shown its beneficial effects on conditions such as depression, anxiety, panic attacks, eating disorders, post-traumatic stress, hypertension and cardiovascular disease, but the systematic review in order to assess the degree of scientific evidence of meditation techniques, showed a lack of appropriate methodology in published studies, which prevented the accurate analysis of the effect of meditation techniques in different clinical conditions [15].

Studies to assess whether parents of children with chronic diseases would benefit from a similar program are rare [16]. An increasing number of patients with chronic kidney disease (CKD) depend on non-

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Received: December 17, 2015; **Accepted:** December 30, 2015; **Published:** January 06, 2016

Citation: Kawakami E, Andrade MCD, Couri M, Sales EdS, Cardoso R (2016) Kidneys: Application of Meditation Techniques in Caregivers of Children and Adolescents with Chronic Kidney Disease on Hemodialysis Therapy. J Nephrol Ther 6: 232. doi:10.4172/2161-0959.1000232

professional health caregivers, such as family and friends. However, the needs of caregivers are often neglected and under-prioritized [17]. Systematic review of interventions in informal caregivers of patients with CKD was identified only in three studies, all of which focused on the educational material effect. We conclude that the health care of caregivers should be included in the care chronically ill children [12].

Stress has a negative effect on quality of life, not only that of patients with CKD on hemodialysis, but also of their caregivers. A cross-sectional study in a hemodialysis unit, with 180 patients and 180 caregivers, showed that 75% of patients and 33.4% of caregivers were moderately to severely depressed [18]. The emotional burden increases in proportion to the frequency of hemodialysis [19].

Considering the high levels of burden on caregivers of patients with chronic disease and the lack of intervention studies, the purpose of this study was to evaluate the benefit of meditation practice on the level of anxiety and depression in caregivers of children with CKD undergoing hemodialysis. There is no similar existing study in our country.

Participants and Methods

All caregivers of children and adolescents with CKD undergoing hemodialysis at the pediatric hemodialysis unit at Escola Paulista de Medicina / UNIFESP were invited to take part. The motivation of the caregiver was the main inclusion criteria used, as well as being over the age of 18, during the initial interview with the interviewer, as well as the caregiver´s availability for the practice. Exclusion criteria: caregiver with a diagnosis of severe asthma or chronic obstructive pulmonary disease, psychosis, clinical and surgical complications, alcohol use (more than five units per week), regular practice of yoga, meditation and similar techniques that induce response relaxation (breathing techniques, relaxation techniques, tai chi chuan, etc.), drugs and medication for insomnia and / or tranquillizers.Caregivers unable to participate in most of the sessions (<6/8 sessions), and those who did not comply with the practice of meditation at home (<5 / week), were also excluded.

Methods

Demographic and clinical data of children with CKD and their caregivers were collected using a standardized questionnaire. The "Beck Anxiety Inventory" and "Beck Depression Inventory" were administered before and after the meditation practice intervention program [20,21]. These questionnaires comprisedof 21 multiple-choice questions, with an evaluationof the degree of depression and anxiety using a semi-quantitative scale (0,1,2,3) with four possible responses, signaling the one resembles the mental state of the individual the most. The validated version in Portuguese for the Brazilian population was used.

The Beck Anxiety Scale and Beck Anxiety Inventory (BAI) allows to assess the severity of an individual's anxiety, with collected information concerning the last week, expressed in physical or emotional symptoms of anxiety (like sweating and feelings of distress). Scores are classified by grade: minimal (0-7), low (8-15), moderate (16-25) and severe (26-63). The Beck Depression Scale and Beck Depression Inventory are the most widely used instruments to evaluate the severity of depressive episodes. In its current version the questionnaire is designed for individuals above 13 years of age and consists of various items related to depressive symptoms, as well as physical symptoms such as fatigue, weight loss and decreased libido. The score gradesare: absence of depression (0-9), mild to moderate (10-18), moderate to severe (19-29) and severe (30-63).

Intervention program with concentrative passive meditation technique: The meditation program lasted eight weeks, with 8 weekly meetings lasting 45 minutes. A noise-free room was used, such as an auditorium, with padded chairs, and a quiet environment. During the first 15 minutes of every session, participants received guidance on the meditation technique, explanations of possible benefits and mechanisms of action. After the first session, doubts, frequency of home meditation practice and difficulties faced were included. During the last 15 minutes, we practiced the meditation technique.

Concentrative technique of passive meditation: The participant was instructed to practice meditation seated comfortably in a chair, avoiding excessive flexion of the spine without moving the body, with eyes shut, no movement of the eyeballs, being told to look for an imaginary point located just below the horizontal line of sight, which causes the individual´s eyeballs to focus slightly downwards in a subtly convergent way, and always paying attention tohis/her abdomen movement and breath intakes. There was no interaction among participants during the practice as well as no verbal, tactile or any other form of contact.

Meditation wasperformed according to the concentrative passive meditation technique, described by Cardoso et al. [14]: a) Anchor (autofocus measure), which allows to focus all mental activity on a single focal spot. Abdominal breathing was used, with a focus on its reciprocating motion, and counting the intakes in 3 stages: 1 Inspiration while mentally counting from 1 to 3; 2 Rapid respiratory stop (of about 1 second); 3 Expiration while counting down from 3 to 1. Participants were asked to gradually increasetheir breathing time, until becoming the slowest possible without feeling uncomfortable; b) logic (thought?) Relaxation: it was suggested that the participant observedhis/her flow of thoughts without any interference and as soon as she noticed any overlaying in thoughts, that she redirected her attention and focus on the abdomen and breathe count. It was recommended that, in general, the caregivers should not try to interpret any reactions to the technique.

The mentor signaled the end of the experiment, after which, the volunteers took three deep breaths, slowly opening their eyes and having a minute of silence. The volunteers were instructed to perform the technique daily at home for 15 minutes.

Statistical methods

Quantitative variables were described using the mean and standard deviation or median. The qualitative variables were described by calculating the proportions.

Ethical considerations

The study was approved by the Ethics Committee for Medical Research of the Federal University of São Paulo. After presenting the due clarifications, the participants were asked to sign an informed consent.

Results

7/11 (63.3%) mothers of children and adolescents on hemodialysis who met the inclusion and exclusion criteria, and who agreed to participate were included. The age ranged from 25 to 44 years (mean 34 ± 7.4 years; median: 32 years) and their children from 3 to 13 years (mean: 6.86 ± 3.6 and median: 6.0), with gender ratio F / M: 4/3. Regarding marital status, three were single, three married or living with a partner and 1 was divorced, and the offspring varied between 1 and 3 children (median: 2). As for education level, 1 had completed only elementary and 6 high school, and regarding their socioeconomic status, according to the criteria of the Brazilian Association of Research

Companies [22], six families belonged to the C level (household income >2,300, 00 reais and <4,600.00 reais) and the D level (household income >1,400.00 reais), 5 of them wereresponsible for their family's income.

Meditation sessions coincided with the hemodialysis day, which occurred 3 times/week, in order to facilitate adhesion and thus the caregivers of children who underwent hemodialysis procedures on Mondays, Wednesdays and Fridays, attended the meditation sessions on Mondays, while the caregivers who underwent hemodialysis sessions on Tuesdays, Thursdays and Saturdays, attended on Tuesdays. 5/7 caregivers that did not meet the established home meditation practice mark: two of them dropped out after two weeks, justifying by saying they lacked time and that it prejudiced their child's care, and 3 after their children were hospitalized, were excluded. Only two attended every session, one of them pursuing a regular meditation practice at home with at least 5 weekly sessions, while the other one had irregular or interrupted practice sessions.

The average initial anxiety score of the 7 mothers was 16.3 ± 14.8, ranging from 4 to 40 (median: 10, mild) and depression 13.7 ± 9.9, ranging from 4 to 31 (median: 12, mild to moderate). Anxiety was diagnosed in 100% of cases, with 3 presenting a minimal grade (4, 6, 7), two presenting a low grade (10, 12) and two a severe grade (35, 40). Depression was diagnosed in 4/7 (57.1%), with 3 presenting mild to moderate grade (12, 13, 17), 1 severe grade (31); and 3 did not present depression (4, 6, 7).

The post-intervention questionnaire was answered by the two mothers who attended every session, but adhesion to the study was only achieved by one of them (14%). She presented the same mild anxiety score (12 before and 10 after) and depression (6 before and 5 after), while the other continued to present a severe degree of anxiety (40 before and 38 after), and a worsening in her depressive state, going from mild to moderate to severe (17 before and 23 after intervention).

Discussion

In recent years there has been a growing interest in the quality of life in children with CKD due to higher survival rate and longer life expectancy, but with few interventional studies oncaregiving mothers. We chose to study this group of caregivers for the vast existing psychological tension which affects children and family throughout the course of the disease and its treatment [23]. However there were many limitations, such as small sampleand poor adherence to the meditation practice, complicating any comparative analysis of the variables before and after the intervention. It was observed that of 100% of the mothers and caregivers over 50% showed anxiety and depression, respectively.

The exact physiological effects of meditation differ from one person to another, and depend on the meditator's experience and discipline. However, in general, meditation can bring profound physical, psychological, emotional and spiritual benefits. These tend to increase with a more frequent meditation practice and are more pronounced in experienced meditators. Meditation causes a reduction in the body's metabolism, which results in a decreased heart and respiratory rate, and decreased oxygen consumption; as well as reduction of stress reactions, reducing the harmful effects it has on the body.

The adhesion rate to the intervention was much lower than expected (14%) considering the stress that they are subjected to due to the painful treatment of dialysis, during which patients internalize that they depend on a procedure or a health care team and hospital structure, and on the other hand the family, with the shock of the fact that it is an incurable disease with an imminent risk of death [3].

Different people may have different levels of needs, and hence different levels of motivation for the regular practice of meditation. The levels of human needs differ - and one of the features that differentiate men from animals would be the human hierarchy of needs –and are much more complex than in other species: physiological, safety, social, self-esteem and self-realization, in this exact order [24]. Meditation could interfere only in motivational parameters relating to self-realization through meditation practice. In this way, meditation would not be the method of choice in an extremely poor population, or adolescents, with their thirst for socialization, as they face difficulty in practicing meditation outside of a group context.

The difficulty regarding adherence could also be related to the difficulty of getting in touch with themselves, whether in order not to look at one's narcissistic wound - "the failure" of the reality of the real child as opposed to imaginary/expectation - or the life story they have, in which they had no opportunity to reflect and dedicate a time to listen to themselves [25]. Thus, these mothers have acquired a thick layer of skin throughout life, in order to preserve and protect themselves from external reality and from themselves. Therefore they abdicate their own lives in order to care for their children, and are in a constant state of alert and concern, with many thoughts and feelings going constantly through their minds, so that meditation, an activity which concentrates all mental work on a single focus point, preventing the formation of thought sequences with relaxation of the mind and subsequent psychophysical relaxation, is a great challenge and a threat to their defense mechanisms [25].

Other factors could have an impact other than the caregiver's burden, such as: age, the presence of other small children, difficulty to arrange time, lack of space for home practice of meditation, socioeconomic level and trouble with the passive concentration meditation technique used. Difficulties to remain seated in an isolated environment may also be a factor that interfered in this population, and the application of other meditation technique could have been tested. Thus, the results clearly showed the difficulty of adherence to this technique in this population of caregivers, and perhaps a more intense work with another type of intervention is needed.

Treatment and clinical well-being programs using meditation, based on the technique of Mindfulness-Based Stress Reduction (MBSR) have increased in number, and there are currently more than 250 programs in North America [26]. A study involving adults with multiple severe disabilities using this technique was performed, both for patients and for caregivers, for a period of 8 weeks, and showed a significant increase in the level of happiness among participants [27]. There was improvement in QOL of caregivers through greater awareness of their own cognitive biases on the perceived and actual vulnerability, while providing support in relation to child protection, reducing the level of unnecessary worry, and also of symptoms associated with stress. Kabat-Zinn et al., reported that physical and psychological support promote positive results in different clinical situations [28]. Furthermore, MBSR has proved effective in complementary treatment, in studies of patients suffering from chronic pain, fibromyalgia, anxiety, panic disorders, psoriasis, depression, cancer and in heterogeneous populations [29]. As well as the stress reduction technique based on the MBSR technique, self-applied breathing techniques and relaxation with guided imagery, to primary caregivers of patients with chronic diseases, have presented positive results [28-30].

As regards to cognitive-behavioral therapy (CBT), a meta-analysis study shows a lack of studies, small sample sizes, inadequate study design and heterogeneous approach to various forms of psychotherapy,

which hinders the actual analysis and reproducibility of the effects of CBT in most examined medical conditions [31].

Recently, a semi-quantitative method was developed using 57 selected items, based on interviews with 10 caregivers and 17 professionals involved in the care of patients with DRC [32]. However, different stages of treatment (dialysis or post-transplantation) can lead to different levels of quality of life in children with CKD, and reflect as such on their parents/caregivers [33]. The QOL level may be lower in children with CKD undergoing hemodialysis, compared to conservative treatment and peritoneal dialysis. A study on 203 children with CKD (hemodialysis, peritoneal dialysis and conservative treatment) and their 388 parents or guardians showed that QOL scores for all groups were significantly lower in all areas compared to the general population, being lower in the hemodialysis group [3]. In our country, Koch et al reported that children and adolescents with CKD in stages 4-5 have lower QOL scores than their healthy peers and that there is a progressive worsening of these parameters with age. They found in this study, a trend of divergence between the quality of life of pediatric patients and their caregivers, and that caregivers often underestimate the effects of the disease on the quality of life of their children [34]. Another study showed that patient's age >10 years, and the absence of religion were significant for the lowest overall score of QOL. The CKD group presented a higher proportion of behavioural and emotional disorders in all fields, and negative correlations between emotional and behavioural disorders and QOL score. The authors suggest the importance of assessing the behavioural and social effects of CKD in order to improve the quality of life of this pediatric population [35]. The same group of researchers noted the need to know the reactions and the difficulties experienced in peritoneal dialysis of 30 children and adolescents with CKD and their caregivers, through a non-standardized questionnaire with open and closed questions in descriptive study [36]. The answers were related to fear of infection, inconveniences related to the procedure, inadequate conditions for the procedure (room and equipment), and decreased quality of life of family.

Another study based on educational program (nutrition, dialysis, fistula and catheter care, information about DRC, blood pressure, weight control, hygiene, exercise) in patients undergoing hemodialysis, showed a decrease in the burden of 122 patients caregivers. Among the caregivers, the average score of the "Zarit Caregiver Burden Scale (ZCBS)" was significantly higher in women, young men, family relatives (daughter / sister / brother / stepdaughter) and with high level education ($p<0.05$). The post-secondary mean values (55.0 ± 7.6) caregiver burden was significantly lower than the pre-educational score (43.9 ± 5.2). With the development of CKD and installation of ESRD, one of the symptoms in the decrease in quality of life symptom is fatigue, and depression is recognized as the most common problem. Nocturnal hemodialysis causes a heavy burden and worsens the quality of life of caregivers of patients with end-stage CKD. However, the self perception of burden for caregivers and patients is relatively low, although a significant proportion of them present depression (47% of patients and 25% of caregivers). Other innovative approaches are needed to support caregivers and patients undergoing nocturnal hemodialysis, in order to reduce the risk of developing depression. Apartfrom these effects, changes in the caregivers' sleep-wake patterns are commonwhen caring for patients with chronic disease. The development of truly effective interventions to improve the quality of sleep of patients and their caregivers would be very promising [37-39].

Finally, the physical and emotional burden on caregivers of patients with chronic disease appears to be well recognized, but there is a lack of interventional studies and even fewer on parents of children with CKD. The most commonly offered assistance given to parents is information about the disease and how to address the symptoms, and more research is needed to identify new strategies to compensate for stress, anxiety, depression and quality of life of the caregiver [40].

Conclusion

Although there are many limitations in this intervention study with the practice of concentrative passive meditation, the high rate of anxiety and depression detected proves that it is necessary that the medical staff recognize this problem, for an early approach, with some kind of intervention that is beneficial for these caregivers and consequently for sick children.

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