



Parental psychological stress: Children on hemodialysis

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1. Introduction

In Jordan, a national survey revealed that the prevalence rate of end stage renal disease (ESRD) cases was 312 per million (Annual Report Jordan, 2012). Additionally, five to ten children per million are diagnosed with ESRD each year, and 20% of such cases result in mortality within the first year after diagnosis (Annual Report Jordan, 2012). ESRD usually needs long-term invasive medical treatment (Buiten et al., 2014). In Jordan, hemodialysis (HD) is the most common selection for patients with ESRD. HD is a long-term course that does not ultimately cure, but rather helps body functions to perform normally for longer periods of time (Kallenbach, 2015). The long duration of hemodialysis may affect the psychological status of the patient and their interactions with their environment. Therefore, health care providers should offer holistic care integrating patients' physical, psychological and spiritual needs, including their social environment in the care process.

Regardless of the massive development in the technology of dialysis and the increase in the life anticipation of patients on HD, the procedure and its consequences are still stressful for the patients and their families, especially if the patient is a child (Buder et al., 2016; Kheir, 2016). Children undergoing HD may face some physical complications such as headache, vomiting, muscle cramps and fatigue (Mohammed, 2014). Additionally, children have to restrict their diet and fluid intake, and have to use numerous medications accompanied with recurrent visits to hospital to undertake dialysis (Ayestaran et al., 2016; Levy Erez et al., 2016). All of these have negative psychological impact on the child, parents and family system (Barlow & Ellard, 2006; Kiliš-Pstrusińska et al., 2013; Medway et al., 2015; Neul, Minard, Currier, & Goldstein, 2013).

Children receiving HD are more vulnerable to psychological problems such as anxiety, depression, sadness, and reduced Quality of Life (QoL) than patients diagnosed with many other chronic diseases (Assadi, 2013; Kaur & Davenport, 2014). Psychological effects of HD on children were investigated. Anxiety and depression were reported in children newly receiving HD (Moreira, Soares, Teixeira, e Silva, & Kummer, 2015). For example, the sight of blood running through tubes and the alarms of the equipment were found to provoke anxiety for child patients newly undergoing HD (Moreira et al., 2015). Depression

was the most common psychological issue highlighted by the children, with a prevalence ranging from 20 to 90% (Kheir, 2016). This is important since anxiety and depression may affect the primary medical problem, their social surroundings and the outcome of the treatments (Lustman et al., 2000).

Children receiving HD may feel isolated from their families and peers (Cousino & Hazen, 2013). They often suffer from growth and development retardation, delayed development of secondary sexual appearances. Moreover, they might have multiple surgical scars due to multiple insertions of the HD catheter or performing a fistula (Almási-Sperling et al., 2016). In addition, many children on HD reported having fatigue, insomnia, anorexia, and psychomotor problems, all of these may affect children and their parents (Amr et al., 2009).

Parent of children on HD have to change their lifestyle to adapt with this situation, and have to deal with their child's emotional conditions. Such parents are generally very apprehensive and fearful about their children's future (Tong, Lowe, Sainsbury, & Craig, 2008). Stress levels of parents of children with chronic disease in Jordan were compared to parents of children with cancer and parents of healthy children. Findings showed that parents of children with cancer had the highest stress levels among the groups, although the sample did not include children with ESRD (Masa'Deh, 2015). A number of studies on children diagnosed with chronic diseases and their parents have frequently found that some children and their parents face considerable risk of stress. Later, this group of population developed symptoms of post-traumatic stress disorder (Masa'deh & Jarrah, 2017; McCann, Bull, & Winzenberg, 2015). It is acknowledged in the literature that parenting an ill child is stressful and is accompanied with new parental roles and responsibilities (Cousino & Hazen, 2013).

Children receiving HD present unique challenges to their parents and healthcare providers. However, these challenges have not been studied extensively (Nicholas, Picone, & Selkirk, 2011). Parents of children on HD need to adapt to stress to be able to support their children (Watson, 2014). In particular, increased social support can decrease the levels of stress, increase perceived QoL, and increase patient compliance with prescribed therapy. Social support also has a direct physiological effect on the immune system through a number of mechanisms, in which social support has a positive effect on the parents

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and their children (Cohen, Janicki-Deverts, & Miller, 2007). Additionally, the caring process for those patients should be comprehensive, and health care providers should focus not only on the needs of the patient but also on their families, as the relationship between the ill child and the family is crucial and affects both sides. Adding the social part to the caring process is central to holistic care.

The fact that HD is still considered as one of the best solutions for the survival of children suffering from chronic kidney disease is reflected by the number of Jordanian children who visit hospitals frequently for this purpose (Annual Report Jordan, 2012). Therefore, many families experience stressors and develop some psychological problems related to having a child who is on dialysis and they require special attention from health care providers physically and psychologically. The literature search did not identify any previous studies in Jordan related to stress in parents of children on HD. Therefore, the present study examines stress in parents of children undergoing HD in Jordan to answer the following research questions:

- What are the levels of perceived stress of parents of children undergoing HD?
- What are the differences in parental stress levels according to patient and parental gender, vascular access method and parental financial status?

2. Methods

2.1. Design

A descriptive cross-sectional correlational design was used in this study.

2.2. Ethical considerations

Ethical approval was obtained from the Institutional Review Board (IRB) at the Applied Science Private University (#Faculty 015). Access was granted to the public, private and teaching hospitals where the study has been conducted.

2.3. Data collection procedure

The study team comprised the main researcher and two renal nurses licensed as research assistants. After getting the ethical approval, the research assistants visited the ward managers in the selected hospitals/ departments where they distributed the information sheets and obtained informed consent from parents who wished to participate. Parents were advised that participation in the study was voluntary and responses to the questionnaires were confidential. Participating parents completed the questionnaires and returned them to the research assistants or the main researcher. Data was stored in a secure place and not used by anyone but the main researcher without the consent of the participants. Aggregate data was used for publication purposes.

2.4. Participants, sample and settings

Sample size calculation was carried out using Sample G Power software. To reach statistical significance with a power of 0.8 and an α of .05, a sample size of 150 was necessary. A convenience sample of 160 parents of children on HD was recruited from six major pediatric hospitals that provide HD services for children (i.e. two public, two private and two teaching hospitals) in the three largest cities in Jordan (Amman, Zarqa and Irbid). The inhabitants of these cities comprise more than 75% of the Jordanian population, making them highly representative of the national population, and patients from other areas conventionally commute to major cities to receive HD (Jordanian Department of Statistics., 2008). Statistics have shown that these hospitals treat more than 87% of the childhood dialysis patients in the

country (Annual Report Jordan, 2012). Participants were included if they met the following inclusion criteria: a) parenting one child on HD; b) holding Jordanian nationality; c) older than 18 years; and d) literate (able to read and write) in Arabic. They were excluded if they had: a) a diagnosis of mental illness; b) a diagnosis of a serious disease not related to HD (e.g. cancer); c) a dying child/family member with life expectancy of less than a month.

Data were collected over a one-year period (i.e. from April 2016 to April 2017). 185 parents were invited to participate, of whom 165 consented, and 160 ultimately completed and returned the questionnaires and were included in this study (a response rate of 86.49%).

2.5. Instruments

2.5.1. Socio-demographic data and characteristics

Socio-demographic data were collected through a developed Arabic list that included information about participating parents, the ill child and the family. Information about parents included age, gender, financial status, employment and level of education. Additionally, data were collected regarding variables such as the age and gender of the ill child, duration of dialysis session, frequency of dialysis per week, number of years receiving dialysis and type of vascular access, along with the number of family members and health status of all family members. Previous literature supported that such information may contribute to parental stress (Cousino & Hazen, 2013).

2.5.2. Arabic version of perceived stress scale 10-items (APSS10)

The Arabic Perceived Stress Scale 10-Items (APSS10) is a rating scale ranging from never (0) to very often (4). The scores can range from 0 to 40, with higher scores representing higher stress levels (Cohen & Williamson, 1988). The APSS10 is not a diagnostic instrument, so there are no cut-offs; there are only comparisons between people in a given sample. The APSS10 has been used to assess perceived stress levels in a normal population in various cultures and countries, including Jordan (Cohen & Williamson, 1998; Masa'deh, Bawadi, Saifan, & AbuRuz, 2015). Masa'deh et al. (2015) used an Arabic version of PSS10 (APSS10) to study stress among parents of healthy children in the normal population in Jordan and reported an internal consistency of 0.89. It has also been used to measure perceived stress of relatives of people with health problems (Masa'Deh, Collier, & Hall, 2012). All of these supported the validity of the APSS10 to be used for Jordanian parents of children receiving HD. In this study, the APSS10 was used to measure the stress level of parents of children on HD.

2.6. Data analysis

Descriptive statistics was conducted to describe the study sample and their demographics. In order to answer the first research question, mean and standard deviation (SD) were calculated for APSS10. To answer the second research question, an independent samples *t*-test and ANOVA was conducted (depending on the variable). The reliability of the APSS10 was confirmed by a Cronbach's alpha coefficient value for the overall scale of 0.84, suggesting very good internal consistency and the reliability of the scale within this sample.

3. Results

As reported in Table 1, the participants ($n = 160$) were Jordanian parents of children on HD in Jordan. The age of parents ranged from 24 to 60 years, with a mean of 35.23 ± 6.86 . Mothers represented 53.8% of the participants and the rest were fathers. Results of this study showed that employed parents form 58.1% of the overall sample. About 92% of fathers and 13% of mothers were employed. The average of number of children in the families of participating parents was 2.83 ± 1.36 . Participants had to travel to reach the hospital; the mean distance to the hospital was 51.56 ± 68.43 km. The mean frequency for HD was 3.16 times per week

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