

Improving Children's Quality of Life during Haemodialysis via Nursing Interventions

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Abstract

Background: Strict dietary and lifestyle changes are necessary for children with chronic kidney disease (CKD), but little is known about their quality of life in this context. We set out to compare HRQOL among groups of children with varying degrees of chronic kidney disease (CKD) with a healthy control group.

Methods: Using the PedsQLTM Generic Core Scale, a cross-sectional evaluation of HRQOL was conducted for the following domains: physical, emotional, social, and school. Twelve children on maintenance haemodialysis or peritoneal dialysis (DIAL) and twenty-seven children with kidney transplants (TX) were included in the data set, along with twenty children with chronic renal insufficiency (CRI; creatinine >200 µmol/l). The following numbers were collected from caregivers: 20 for CRI, 17 for DIAL, and 21 for TX. Using analysis of variance (ANOVA), we compared the CKD groups; t-tests were used to compare our CKD samples to the controls.

Summary: In every subscale, children with CKD performed worse than the controls; however, the difference between the controls and children with TX was statistically significant ($P < 0.02$). Children in the DIAL group outperformed the TX group across the board. The physical subscale showed a significant result for the analysis of covariance with number of drugs as a covariate ($F = 8.95$, $df = 3, 53$, $P = 0.004$). In each of the four categories, patient scores were higher than those of the proxy caregiver. Children with chronic kidney disease report a worse HRQOL compared to the healthy control group. Caregivers may find comfort in the fact that children undergoing dialysis report a higher-than-expected HRQOL. Nevertheless, it is concerning that the children of caregivers did not share their perception of better HRQOL following transplantation in this study.

Keywords- healthcare, hospital, pneumonia, ventilator, haemodialysis

1. Introduction

As a chronic condition, end-stage renal failure significantly lowers patients' health-related quality of life owing to the impairments and restrictions that patients experience in nearly every aspect of their everyday lives.

Patients undergoing hemodialysis undergo a difficult procedure that necessitates multiple trips to the hospital or dialysis clinic, typically three times weekly. This causes patients to significantly alter their daily routines. Research into the efficacy of treatment interventions, survival rates, and hospitalizations can be greatly enhanced by measuring health-related quality of life, which also serves as a predictive indicator of disease outcomes. There is still a 30-fold increase in their mortality risk compared to children who do not have kidney disease.¹ In the absence of a kidney transplant, children suffering from ESKD are treated with hemodialysis (HD) or peritoneal dialysis (PD). There is no break in the dialysis routine, and the procedures are intrusive and unpleasant. They have to keep track of many prescriptions and adhere to stringent dietary and fluid restrictions.

Individuals in this group have shown signs of depression, anxiety, social isolation, behavioral issues, a fear of public schools, stunted physical and mental development, and reduced cognitive abilities. Young people who had long-term dialysis as children have documented social repercussions like unemployment and dependence on caregivers as adults. Nevertheless, there is a lack of knowledge regarding this subject. Multiple potential benefits could be obtained by combining the results of different qualitative research. Various viewpoints and experiences spanning many eras, locations, and circumstances.

In order to better the medical, health, and psychosocial outcomes for young dialysis patients, this systematic review sought to synthesise qualitative research on the perspectives of children and adolescents living on dialysis. The findings can be utilized to inform health service delivery and policy. It is possible that the rising prevalence of diabetes and hypertension in Brazil is contributing to the steady rise in the prevalence of chronic kidney disease (CKD), which affects 5–10% of the population (1). With an increase of 20,000 patients in the past four years, the number of Brazilians enrolled in dialysis programs has skyrocketed from 42,695 in 2000 to 112,004 in 2014, up from 92,091 in 2010. Results from the 2014 Brazilian Chronic Dialysis Census demonstrated an uptick in both the incidence and prevalence rates of dialysis treatment compared to 2013 (2). Population longevity and quality of life are also linked to these statistics.

Excessive phosphorus (P) consumption, decreased P clearance, and bone remodeling conditions cause hyperphosphataemia in the majority of chronic renal patients on hemodialysis (4). Cardiovascular illness, secondary hyperparathyroidism, and decreased calcitriol synthesis are all associated with elevated P levels in patients with chronic renal disease (3). An elevated mortality risk is also associated with alterations in phosphate and calcium metabolism in this group (5-6). The suppression of 1α -hydroxylase, the enzyme responsible for calcitriol synthesis, is one of the actions of fibroblast growth factor 23 (FGF-23), which was discovered over a decade ago. This discovery uncovered fresh information regarding the processes of phosphorus control linked to mortality in patients with chronic renal failure. Renal adaptation happens in the early stages of chronic kidney disease (CKD). It's marked by a rise in phosphaturia in the surviving nephrons and a decrease in tubular reabsorption of phosphorus. Elevated parathyroid hormone (PTH) levels sustain this process (6). This compensatory mechanism is unable to keep phosphate levels within the normal

range as the glomerular filtration rate (GFR) gradually declines. Secondary hyperparathyroidism, metastatic calcifications, cystic fibrous osteitis, and its role in the development of renal failure are among the hyperphosphatemia's consequences. Other symptoms include pain, osteopenia, anemia, hypertension, atherosclerotic vascular disease, pruritus, and sexual dysfunction.

The nurse's role in educational activities can facilitate this trifecta. The goal of the educational nursing intervention is to help patients better comprehend their condition and its treatment options so that they can better adhere to their prescribed regimen. To improve the quality of life of this population and decrease disease-related morbidity, the intervention can take the form of printed information like educational materials, as well as individual or group guidance, with the goal of teaching people how to take care of themselves, which is a topic of treatment.

In light of the foregoing, this research has the potential to improve the standard of treatment for renal failure patients. By improving the evaluation of patients' quality of life and increasing their understanding of the condition and hyperphosphatemia treatment, educational interventions help mobilize patients to adhere to treatment regimens, reducing complications, morbidity, and death.

2. Approaches to Nursing Intervention

Any time a nurse performs a treatment, procedure, or instructional moment with the goal of enhancing the patient's health and comfort, this is known as an intervention. These measures might range from making little adjustments to the patient's sleeping environment to more extensive interventions like psychotherapy and crisis counselling. Nurse practitioners can use evidence-based practice to create orders for nursing treatments, in addition to the interventions that doctors already prescribe. Here are some common nursing interventions:

(i) Providing support and care at the bedside (ii) Administering medication (iii) Assisting with feeding (iv) Keeping tabs on vital signs and the patient's progress during recovery (v) A nursing justification explains why a nurse might intervene in a patient's care. The term "nursing intervention" refers to the steps taken by nurses to assist patients in reaching their health objectives. The nursing care plan includes a justification for each nursing intervention.

Keep a careful eye on the vital signs and other symptoms of the elderly individuals who have severe pneumonia. Excluding indicators, such as hypoxemia with or without excessive carbon dioxide, requires a thorough evaluation of the patient's health in order to identify potential risk factors. As part of routine treatment, they should keep an eye out for irregular breathing patterns; when ventilation fails, the body experiences hypoxia, and the patient may exhibit respiratory symptoms such symptom changes. Patients experiencing a drop in blood pressure should also be evaluated for septic shock if they also have a drop in body temperature, since these are the primary symptoms of the condition. Atypical symptoms often manifest early in patients whose brains are severely hypoxic, ischemic, or experiencing carbon dioxide retention. Consequently, in order to avoid the occurrence of critical illness, it is important to notify patients with changes in condition to the attending physician promptly.

Respiratory tract care is equally critical in the treatment of severe pneumonia in older patients using humidification respirators. Continual humidification of the respiratory tract, drug ultrasonic atomization, auxiliary shot back expectoration, and efficient sputum suction are the four fundamental components of respiratory tract treatment. The first is the process of continuously moistening the respiratory tract. Mucinous secretions, decreased respiration or arrest of tracheal mucosal ciliary movement, phlegm that is difficult to cough out and can even form a phlegm plug, difficulty breathing due to obstruction of the respiratory tract, purple lips, and other respiratory symptoms are observed in elderly patients with severe pneumonia caused by infection and other factors. The use of a humidifier improved the patient's capacity to clean their respiratory tract, which contributed to their recovery to some extent. Because of its easy operation and extremely effective properties, the humidifier progressively supplanted the traditional method of humidification in therapeutic practice.

Similar to the treatment group, the study group received psychological nursing care. Those in the treatment group received standard care during hemodialysis. The three stages of psychological nursing evaluation are before, during, and after dialysis. Dialysis patients and their doctors should have an open and honest conversation before starting the treatment. Also, you need to know what the patient needs psychologically and how they're feeling mentally. The nurse should engage in an active conversation with the patient, listen patiently, and try to understand the patient's poor mood before administering psychological therapy. It is critical for nurses to provide comprehensive evaluations of diabetes and uremia to patients who have never visited a doctor. Patients' understanding of their illness and comfort level with hemodialysis will both improve. It is imperative to employ suitable languages or dialects when communicating vital information on hemodialysis and issues encountered during dialysis. In order to meet the needs of patients from all walks of life, this is essential [16, 19].

To quickly identify the patient's pain while they are on dialysis, it is crucial to monitor the numerical deviation of the machine and any changes in the patient's vital signs. Additionally, it is important for the nurse to visit the patients on a regular basis to check in with them, confirm their existence, and provide them with guidance on good posture and updateable, suggestible conversation. One positive aspect is that patients will have something to occupy their time, which will take their minds off of the pain of hemodialysis. To help hemodialysis patients with uremia learn about their conditions and develop disease-resistant confidence, it is recommended that they receive a disease-related newspaper, brochure, or magazine. The nurse's role following dialysis is to help patients get dressed, check in on how they're feeling, and tell them to rest. Assuming they are pain-free, patients will also be able to go. When communicating with elderly relatives, it is essential to keep the patient's psychological needs in mind at all times. This will allow the patient to get relevant and timely concerns from their loved ones. In addition to serving as a psychological signal, treating these concerns may substantially boost a patient's confidence, which in turn has a significant impact on therapy, since these fears are often manifested in certain areas of life. For patients with chronic end-stage renal disease (ESRD), maintenance hemodialysis is a crucial replacement therapy. Reasonable and accurate nursing interventions are crucial for MHD patients because the

treatment is long-term and mostly done outside of a hospital. Malnutrition, severe anemia, infection, and dysfunction of the heart, lungs, liver, and other organs are among the many consequences that patients with uremia often have. Additionally, their residual renal function is often quite poor.

3. Techniques

The study's participants were children from the nephrology clinics of Toronto, Canada's Hospital for Sick Children, ranging in age from two to eighteen. The study's Research Ethics Board gave its stamp of approval. If a patient was under the age of 16, their parent or legal guardian's written informed consent was required; otherwise, verbal consent was taken.

Any patient meeting the following criteria was considered for inclusion: chronic renal illness (CRI), defined as a plasma creatinine level greater than 20 $\mu\text{mol/l}$, end-stage renal disease (ESRD) necessitating maintenance dialysis, or history of kidney transplantation. We did not include patients who met the following criteria: (i) were admitted to the hospital in the last 14 days or for a non-renal comorbidity in the last 30 days; (ii) had a kidney transplant in the last 3 months; (iii) started or changed dialysis modalities in the past 30 days; or (iv) had a major life event, like a family member's death, in the past 30 days, unless it was directly related to their kidney disease.

4. Examining HRQOL

The Core Scales of the Paediatric Inventory of Quality of Life (PedsQLTM Version 4.0) were used in this cross-sectional assessment of HRQOL. A number of chronic diseases, such as asthma, cancer, and diabetes mellitus, have been tested in children and adolescents using the PedsQLTM, which was developed to assess HRQOL [11–13]. Respondents are asked to rate the patient's functioning in four areas: physical (8 questions), emotional (5 questions), social (5 questions), and school (5 questions) in the 23-question survey. The kid self-report and caregiver proxy-report formats are used. Toddler (2-4) (caregiver proxy-report only), early child (5-7 years), older child (8-12 years), and teen (13-18 years) are the four versions of the PedsQLTM that are currently available. When a patient was found to have a developmental delay, the PedsQLTM was given to them based on their developmental age, as established by the attending physician.

Each patient was given an age-appropriate survey once. A qualified interpreter was employed in cases when a parent or patient could not read the PedsQLTM because of a language barrier. The same investigator (A.M.M.) verbally administered the self-report forms to elderly patients with visual impairments and to young children (5-7 years old). Higher HRQOL was indicated by higher survey scores, which ranged from 0 to 100 for each subscale.

5. Information about patients

Details regarding the patient's main diagnosis, date of diagnosis, length of illness, length of time on transplant or dialysis, number of hospitalizations or clinic visits in the last six months, medications, serum creatinine value, and presence or absence of significant non-renal comorbidities were gathered through a review of medical records. Interviews were

carried out with parents or guardians of school-aged children to ascertain their current academic standing, number of days absent from school in the past six months, and the necessity of special education services, such as personalized education programs or supplemental tutoring.

6. Evaluations based on statistical data

Dissimilarities between groups

This study used Student's t-test to compare the three groups' means to those of a healthy children's sample reported by Varni et al. [14]. The HRQOL of individuals with several different chronic conditions has been compared using this control sample [11–13]. Each of the three groups that made up the sample—CRI, dialysis, and transplant—had their mean HRQOL ratings computed for the physical, emotional, social, and school subscales. All four subscales were subjected to analysis of variance (ANOVA) to compare between-group differences. Additionally, each subscale was compared across caregivers and children using the ANOVA. A Bonferroni correction was utilized for multiple comparisons in all analyses.

Children with chronic kidney disease (CKD) and significant non-renal comorbidities were compared to children without such conditions, mothers were compared to fathers, children on PD were compared to children on HD, and children with and without urological diagnoses were also compared using Student's t-tests for the PedsQLTM domains.

7. Assessment of health-related variables

To assess their impact on HRQOL, the following variables were subjected to analysis of covariance (ANCOVA): age at the time of questionnaire administration, age at CKD diagnosis, medication usage, number of outpatient clinic visits in the previous six months, duration of current modality, and plasma creatinine (CRI and transplant children only).

In order to determine the dependability of the parent-child ratings, the intraclass correlation coefficient (ICC) was used [15]. When comparing two raters using the same scale, the ICC is employed; a number greater than 0.9 indicates excellent agreement, while a score of 0 indicates total disagreement.

Table. Patients' demographic

Clinical Variable	CRI(n=31)	DIAL(n=18)	TX(n=38)	P-value
Mean (age)	14.6(4.6)	13.8(4.2)	15.1(3.2)	0.76
2-4 years (female)	0(0)	4(1.8)	0(0)	-
5-7 years (female)	3(0)	2(0)	2(0)	-
8-12 years	5(1)	6(5)	7(0)	-

(female)				
13-18 years (female)	15(7)	9(5)	21(8)	-
Sex(%female)	8(36.1)	10(54)	11(41)	0.46
Mean (SD) length on modality	63.6(76.6)	26.8(23.4)	63.7(48.6)	0.21

8. Conclusion

From June to August 2005, a total of 64 individuals with chronic kidney disease and/or main caregivers were enrolled. Dialysis was used by 17 patients, CRI by 20, and kidney transplantation by 27. Twenty-one children with chronic renal illness (CRI), twenty-six children who underwent a kidney transplant, and twelve children on maintenance dialysis (four of these patients were too young to fill out the questionnaire, and one was unable to do so because of a developmental delay). Seventeen caregivers of children receiving dialysis, twenty of children with chronic renal illness, and twenty-one of transplant kids had their data gathered in a proxy capacity (six children did not have a caregiver present at their clinic consultation). Table 1 displays demographic and clinical data collected from patient interviews and medical records reviews. The majority of transplant patients' hospitalization reasons had nothing to do with rejection; in fact, just three out of ten patients admitted over the last six months underwent kidney biopsies on the suspicion of rejection. In Table 2 you can see a list of patients who have serious non-renal complications.

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