



RESEARCH ARTICLE

Life's Style of Children with Maintenance Hemodialysis in the Middle of Delta

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Abstract

Children with chronic renal failure with maintenance hemodialysis face many problems. These problems are originating either from the disease itself or its management. **The aim** of this study is to identify the life's of children with maintenance hemodialysis. The study included thirty children with maintenance hemodialysis at Pediatric Nephrology Unit at Tanta University Hospital, El-Mansora Pediatric University Hospital, and El-Menotia University Hospital, and El-Menofia University Hospital. Children's age from 6-16 in both sexes, and free from other metrical tiscases. A structured questionnaire sheet was used including four parts. The first part included biosocial data of children and their parents. The second part was used to elicit of information about the history of renal disease, the third part was dated to the history of hemodialysis, and the final part included lifestyle assessment sheet as family living activities (nutritional habits, sleeping patterns, personal hygiene, case of fistula and physical exercises), psychological conditions of children, spiritual attitudes, self-satisfaction and actualization, social relations, and family relations. **The results of this study indicated that the:** majority of children's lifestyle were affected. Conclusion the children with chronic renal failure and hemodialysis had many negative impacts on physical status, daily activities, psychological condition, social relation and spiritual aspect of children's life. **Recommendations:** children need collaboration from parents, nephrologists, nurses, psychologist, and school personals to help them for maintaining and improving physical status, daily activities, psychological conditions, social relations, spiritual attitudes, and school achievement.

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INTRODUCTION

"Children with Chronic Renal Failure (CRF) are at higher risks for behavioral and emotional problems compared to physically healthy children. Moreover, these children treated by hemodialysis feel that life has no meaning and that the pain will never end. They live under a constant shadow; there is no cure or treatment and there is uncertainty about the future which is considered as a constant challenge to attainment of normal life. Also these children face multiple and frequent dietary manipulation throughout their course of treatment. This occurs at a time when growth and development are at then most dynamic stages and behavior adaptation to eating and making food choices are greatly influenced⁽¹⁻⁴⁾.

Chronic Renal Failure is a chronic illness that causes significant permanent interference with child's life style, physical, emotional growth and development. It also causes a significant social and financial impact on the family interferes with daily functioning that requires effort and personal resources to be coped^(5,6).

The number of patients receiving hemodialysis is increasing tremendously. There are about 600,000 patients worldwide who have been under-going maintenance hemodialysis, in Europe and USA, the reported incidence of chronic renal failure and end stage failure in year 2005 among young people aged 0-15 years is 28 million Child population. In United Kingdom (UK) the prevalence of national renal registry was 12.2 per million of total population⁽⁷⁻¹⁰⁾.

In Egypt, the exact statistical reports about the prevalence of renal failure in children are a rare analysis of health statistics showing that the incidence of children on maintenance dialysis is continuously expanding during the last three decades. According to the statistics of health sector in El Gharbia Governorate in 2005, there are 586 cases of a total population of different ages that are scheduled for maintenance hemodialysis. Statistical records of (Pediatric Nephrology Unit) in Tanta University Hospital indicate that 13 cases of children are scheduled for maintenance hemodialysis besides, 34 cases in El Mansoura Pediatric University Hospital and 8 cases in El-Menofia University Hospital⁽¹¹⁻¹⁵⁾.

A comprehensive management is necessary for helping to minimize any disruption in their life can be maintained. Whether the child is hospitalized or is receiving out-patient dialysis, the nurse is in an ideal position to support the medical plan and provide informed and concerned care. As a primary care giver, the nurse provides ongoing assessment, recognize health problems and initiate actions to correct them. The general responsibilities of dialysis nurse are summarized in the accompanying display. Nurse has an important responsibility to the child and family as the primary patient advocates^(5,16,17).

The nurse can play a master role in early detection of potential renal problems and referral of the child to pediatric nephrologists can often prevent irreversible renal damage. Early and close monitoring of vesicoureteral reflux including periodic urine culture voiding cystourethrograms to monitor degree and any improvement of reflux and renal scans to detect scarring, can sometimes prevent a permanent damage. Renal deterioration and failure may be prevented with the use of antibiotic prophylaxis to prevent recurrent urinary tract infection. Surgical intervention is indicated in some children with severe reflux recurrent and urinary tract infections, despite antibiotic prophylaxis^(18,19). The condition of posterior urethral valves, which occurs in 1 of 8,000 boys, may be detected by a prenatal sonogram. So the nurse should encourage a pregnant woman for antenatal follow up and proper referral^(21,22).

Moreover, the nurse is the key member in helping the uremic child and his families where they are undoubtedly have a knowledge deficit in relation to diagnostic procedures and treatment plan of renal failure. The role of pediatric nurse focuses on providing, understanding and education for those children and their families about their illness⁽²⁾.

The nurse has an important role rule in helping the family adjust to the child's condition. The family's adjustment to the condition assessed during initial and ongoing interviews. The nurse helps them to explore any feelings of guilt or blame about the child's condition and encourages them to express doubts they may have about their ability to cope with the child's future. The nurse should assess the family for prior successful coping strategies and encourage using those additional help from social service and psychology, or psychiatry may be helpful⁽²³⁻²⁴⁾.

Material and Methods Material

Research design:

It is a descriptive study.

Setting:

This study was carried out in three settings:

- Tanta University Hospital Pediatric Nephrology Unit,
- El-Mansoura Pediatric University Hospital Nephrology Unit.
- El-Menofia University Hospital Pediatric Nephrology Unit.

Subjects:

Convenient samples of 30 children were selected from children on maintenance hemodialysis who fulfilled the following criteria:

- Age from 6-16 years.
- Both sexes.
- Free from other medical diseases such as Juvenile diabetes, Heart diseases.

Tools of data collection:

In order to collect the necessary information for the study, the following tool was developed.

A structured questionnaire sheet was developed to obtain the following data from children, families, and records.

Part I:

- Biosocial data of child as, child's age, sex, birth order, level of education, and residence.

Part II:

Lifestyle assessment sheet, it was including.

1. Health and physical functioning activities of daily living:

- Nutritional habits as; appetite change, number of meal per day, preferred restricted food and type of food prepared for the child at home.
- Sleeping patterns as; place of sleeping, number of sleeping hours / day, taking a-nape and sleep problems.
- Physical exercises as; practice of physical exercises and reasons lor not practice

2. PsycTiological and spiritual attitudes:

- Psychological condition of children as; feeling when initiation of hemodialysis, hidden disease from others, sense of differences, accompanying relatives to dialysis unit and degree of dependency.
- Satisfaction was including; self-satisfaction, feeling of enthusiasm, having future plan, disease hinder their future plan and feeling of satisfaction of others.
- Spiritual attitudes as; practice religious obligation, go to mosque/church, feeling that disease as a punishment of Allah, and spiritual satisfaction.
- Social relations of children as; peer relations, teachers' relations, relatives visit, prefer isolation, and seeking for children who have the same disease.

Methods of data collection

- 1- Written approval to carry out the study was obtained from the responsible authorities at the previously mentioned settings after explanation of the purpose of the study.
- 2- Both pediatricians and nurses working in the hemodialysis unit were informed about the role of the researcher to gain their cooperation and secure proper communication.
- 3- Children & their parents consent was obtained to participate in this study.
- 4- The tool of data collection was developed by the researcher according to the recent relevant literature.
- 5- After the development of the tools of data collection, a pilot study was carried out on 5 children to evaluate the clarity and applicability of tool. This pilot study was conducted one month before collection of data.
- 6- Children were interviewed using a questionnaire sheet in hemodialysis unit at previous mentioned setting. Every child was interviewed for 50 - 60 minutes during dialysis session to collect the necessary data using the tool.

- 7- Collection of data for this study was carried out through a period of three months (from the February to May 2007).

Statistical analysis:

Data was coded, analyzed, and tabulated by the researcher. For quantitative variables, the range, mean and standard deviation were calculated. For qualitative variables, the number and percent distribution was calculated.

Results

Table (1) shows the biosocial characteristics of studied children, it was evident that high percentages of the studied children were between the age 14-16 years with a mean age of 14.73 ± 4.56 years. More than half of studied children (60%) were females while 40% were males. More than one third of samples (36.7%) were first birth order followed by third birth order as represented 23.3%. It also illustrated that 40% of children were in primary school while preparatory and secondary school were the same percentage 30%. The majority of studied children lived in rural areas with their family (73.3%, 83.4%) respectively.

Table (2) shows children's physiological and psychological problems during dialysis session. It was found that majority of studied children complained from headache pain and dizziness as it represent 76.7%, 70.0% and 66.7% respectively. While 43.3% of children had nausea and 40.0% had vomiting. Chest tightness and hypertension represent 16.7% and 13.3% respectively. Also flushed face, muscle cramps and colic had the same percent, it represents 10%.

Table (3) demonstrates children's physiological and psychological problems after dialysis session. It was found that the majority of studied children had dizziness, loss of appetite, general weakness and blurred of vision as it represent 76.7%, 63.3%, 53.3% and 50% respectively. While headache, nausea, vomiting, muscle cramps and colic as it represent 20%, 16.7%, 13.3%, 13.3% and 10% respectively.

Table (4) shows the effect of dialysis on children's nutritional habits and children's sleeping pattern. It was found that majority of studied children (90%) had appetite loss. Two thirds of studied children (66.7%) were taking the same family diet and fluid as demand. Regarding sleeping hours / night it was found that slightly more than half of children (53.3%) sleepless than eight hours/ night. The majority of studied children (66.7%) had interrupted sleep.

Table (5) illustrates children's practice of physical exercises. It was found that more than two thirds of studied children (70%) didn't practice physical exercises. As regarding to the reasons of not practicing exercise were not allowed because health condition, easy fatigability, dyspnea and afraid of an accident to fistula as it represented 52.4%, 28.6% and 19% respectively.

Table (6) reveals the effect of dialysis on their school achievement. All children (100%) have irregular attendance to school. Seventy percent of these children have low marks and one third of them (30%) failed in school.

Table (7) illustrates children's spiritual attitudes and satisfaction. It was found that the majority of studied children didn't practice of religious obligation and weren't go to mosque / church as it represent (86.7%, 93.3%) respectively. It was found that only 6.7% of studied children felt that the disease as a punishment of Allah. While the majority of studied children (86.7%) hadn't spiritual satisfaction and only 13.3% had spiritual satisfaction.

Table (8) revealed that the children's social relations. Regarding children-parent relation eighty percent complained parents' over protection and the complaining of not given pocket money and preference of siblings represent 6.7, and 3.3% respectively. More than half of studied children (53.3%) hadn't problem in children-sibling relations, the complaining of violence and incongruent with each other were sari percent, as it represented 16.7%. Also 13.3% of studied children complained their sibling make fun of them.

Regarding children-peer relation it was found that majority of studied children complained of violence and make fun of them as it represent (36.7 and 33.3%) respectively, while less than one third of them (30.0%) we having kindness from their peer. The majority of studied children (80%) weren't visiting their relatives. Also more than half of studied children (53.3%) hadn't relation with their teacher. More than half of studied children (60%) were preferring isolation while 40% of children weren't preferring isolation. Forty percent of them were seeking for children have the san disease.

Table (1): Biosocial Characteristics of Studied Children

Characteristics	N = 30	%
Age in years:		
6-	1	(3.3)
8-	7	(23.3)
10-	1	(3.3)
12-	7	(23.3)
14-16	14	(46.8)
Mean		14.73
S.D.		4.56
Sex:		
Males	12	(40.0)
Females	18	(60.0)
Birth order:		
First	11	(36.7)
Second	6	(20.0)
Third	7 -	(23.3)
Fourth or more	6	(20.0)
Educational level:		
Primary	12	(40.0)
Preparatory	9	(30.0)
Secondary	9	(30.0)
Residence:		
Rural	22	(73.3)
Urban	8	(26.7)
Living with:		
Family	25	(83.4)
Father only	1	(3.3)
Mother only	4	(13.3)

(2): Children's Physiological and Psychological Problems during Dialysis Session

Problems*	N = 30	%
Pain	21	(70.0)
Nausea	13	(43.3)
Vomiting	12	(40.0)
Headache	23	(76.7)
Chest tightness	5	(16.7)
Dizziness	20	(66.7)
Colic	3	(10.0)
Muscle cramps	3	(10.0)
Hypotension	4	(13.3)
Flushed face	3	(10.0)

* More than one problem

Table (3) Children's Physiological and Psychological Problems after Dialysis Session:

Problems*	N=30	%
Nausea	5	(16.7)
Vomiting	4	(13.3)
Headache	6	(20.0)
Dizziness	23	(76.7)
Colic	3	(10.0)
Muscle cramps	4	(13.3)
Loss of appetite	19	(63.3)
General weakness	16	(53.3)
Blurred of vision	15	(50.0)

* More than one problem

Table (4): The Effect of Dialysis on Children's Nutritional Habits and children's sleeping pattern

Nutritional habits	N= 30	%
Appetite loss:		
Yes	27	(90.0)
No	3	(10.0)
Number of meal / day:		
2	20	(66.7)
3	6	(20.0)
>3	4	(13.3)
Preferred restricted food*:	24	(80.0)
Salted diet	20	(83.3)
Dairy products	5	(20.8)
Meat	5	(20.8)
Salty snacks	2	(8.3)
None preferred food	6	(20.0)
Type of food prepared for the child at home		
Special diet	10	(33.3)
Family diet	20	(66.7)
Fluid intake		
Limited	10	(33.3)
As demand	20	(66.7)
Sleeping pattern	N= 30	%
*Place of sleeping:		
Alone	6	(20.0)
With other siblings	5	(16.7)
Beside mother	19	(63.3)
Number of sleeping hours / night:		
<8	16	(53.3)
8	9	(30.0)
>8	5	(16.7)
Taking a nap:		
Daily	2	(6.7)
At the day of dialysis	19	(63.3)
None	9	(30.0)
Having sleep problems:		
Difficulty to sleep	6	(20.0)
Interrupted sleep	20	(66.7)
None	4	(13.3)

* More than one answer

Table (5): Children's Practice of Physical Exercises

Variables	N= 30	%
Practice physical exercises*		
At home	7	(23.3)
At street	2	(6.7)
School	2	(6.7)
Not practicing of physical exercise:	21	(70.0)
Reasons for not practicing exercises: (n=2J)		
Not allowed because of health condition	11	(52.4)
Afraid of any accident to fistula	4	(19.0)
Easy fatigability and dyspnea	6	(28.6)

* More than one answer

Table (6): Effect of Dialysis on School Achievement

Variables	N= 30	%
School attendance :		
Irregular attendance	30	(100)
Dialysis affect on school performance : (last year)		
Failed	9	(30)
Have low marks	21	(70)

Table (7): Children's Spiritual Attitude and Satisfaction

variables	N= 30	/n
<i>Practice degree of religious obligation</i>		
Yes	4	(13.3)
No	26	(86.7)
<i>Go to mosque /church</i>		
Yes	2	(6.7)
No	28	(93.3)
<i>Feeling that disease as punishment of Allah</i>		
Yes	2	(6.7)
No	28	(93.3)
<i>Spiritual satisfaction</i>		
Yes	4	(13.3)
No	26	(86.7)

Table (8): Children's Social Relations as Regard Dialysis:

Social relation	N= 30	%
Children - parent relation:		
Over protection	24	(80.0)
Not given pocket money	2	(6.7)
Preference of their siblings	1	(3.3)
All request are achieved	3	(10.0)
Children - sibling relation:		
Violence	5	(16.7)
Incongruent with each other	5	(16.7)
Make fun of them	<	(13.3)
No problem	16	(53.3)
Children-peer relation		
Violence	11	(36.7)
Make fun of them	10	(33.3)
kindness	9	(30.0)
Children - teacher relation:		
Yes	14	(46.7)
No	16	(53.3)
Relatives visit:		
Yes	6	(20.0)
No	24	(80.00)
Prefer isolation from others: Yes		
No	12	(40.0)
Seeking for children have the same disease		
Yes	12	(40.0)
No	18	(60.0)

Discussion:

Renal pathologies have a hard impact on children's lifestyle. Renal failure is a major health problem and it is considered as the most common chronic disease of childhood. Chronic illness interferes with the individual's ability to function fully as it affects the child interaction with their environment^(2,5). The present study was done with the aim of identifying the lifestyle of children under maintenance hemodialysis. The study will help to highlight the children's needs, common physical, psychological, social problems and other problems such as their scholastic achievements.

The present study showed that more than half of the studied children were females. This finding is supported by **Ramzy** (1999) and **Sabry et al.**, (2005), who mentioned that there was a high incidence of renal disease among female^(11,27). This can be justified by the fact that girls of "low socio-economic classes" spend more time indoors. Poor housing conditions increase their exposure to repeated streptococcal infections which is considered the underlying cause of some renal diseases. This could also be due to customs and traditions of rearing children where boys receive more care and attention than girls do.

The present study illustrated that the vast majority of studied children were live with their parents. These results were promising because children under maintenance hemodialysis heartily need both parents that help them to have normal physical and mental growth. It can also help in minimizing a lot of psychological problems commonly experienced by these children.

During hemodialysis session, the present study revealed that the majority of studied children complained of headache, pain, dizziness, nausea and vomiting. Also, the majority problems after dialysis session were dizziness,

loss of appetite, general weakness, blurred vision, headache and nausea. These findings reflect the changes of children's lifestyle and their psychological conditions.

The present study revealed that 70% of studied children under hemodialysis therapy had a pain caused by the invasive procedures during hemodialysis session. This is in agreement with **Ragab** (1998), who "mentioned that children have an unexpected ability to tolerate prolonged disability caused by their illness, but they can-not tolerate the pain caused by dialysis, repeated sampling and the stress due to prolonged hospitalization^(2,33).

Chronic renal failure like other chronic diseases can be a life-altering condition for the affected persons. It affects lifestyle and daily living. Daily activities are important components of healthy lifestyle and activities include ing nutrition, sleep, personal hygiene, physical exercises and recreational activities; social relations in addition to scholastic achievement⁽⁵⁾.

Nutrition during school age and adolescent period has always a major concern of health. The maintenance of proper nutrition is especially challenging for establishing good health and preventing some common nutritional problems and physical disorders. Sound nutritional practice should be demonstrated to contribute to the physical, emotional well-being, cognitive development as well as the long healthy life⁽³⁾.

The present study revealed that majority of studied children had appetite loss and they had only 2 meals per day. These findings are in agreement with **Sabry's et al.**, (2005), who mentioned that 68% were eating 2 meals / day while only 32% were eating 3 meals, per day⁽²⁷⁾. This finding could be justified by the presence of anorexia related to disease and preferred restricted food. **Allen and Vessey (2004)**, clarified that dietary limitations are necessary in chronic dialysis to avoid biochemical complications and to facilitate adequate dialysis⁽²⁶⁾. While **Hockenberry (2005)**, clarified that children feel deprived when being unable to eat foods previously enjoyed and unrestricted for other family members⁽³¹⁾.

With regard to restricted food, the current study revealed that eighty percent of studied children had preferred restricted food. These findings reflect psychological conditions of these children, and also attributed to the fact that it is difficult to control their dietary habits especially outdoors. In addition, 66.7% of studied children never received a special diet. In fact, no dietary changes have been observed among them as they lived on the ordinary family diet before and after hemodialysis. These findings were confirmed by **Sabry's et al.**, (2005), in their study who mentioned that the poor financial state is joined together with low educational level of the family may make them unable to prepare a special diet for their sick children. Besides, **Kalantar (2001)**, mentioned that the mothers prepare meals from available foods stuffs without paying any attention to the measure of a balanced diet^(27,34). In addition, majority of mothers were illiterate and workers. This could be reflected on the quality of care given to children, and the mothers didn't have enough time to prepare special meals for these children.

The findings of the current study showed that 53.3% of studied children had less than 8 hours sleep a day. These findings are justified by the presence of sleeping troubles. The majority of studied children had interrupted sleep and difficulty in sleeping could be related to dyspnea and psychological conditions of children as anxiety. These results are supported by **Parker et al.**, (2001), who revealed that 85% of people under-going hemodialysis experience major sleeps problems⁽³²⁾.

The present study revealed that more than sixty percent of the studied children were sleep beside the mothers for the reason of children's health status. Regarding a nape, the present study clarified that majority of studied children take a nap in a day of dialysis session. It could be related to exhaustion, being drowsy and sleepy after dialysis session.

Physical exercises are an important component of a healthy life style. It is well-documented that physical exercises improve the physical, mental and social well-being. It is also associated with enhancing self-esteem and confidence; also, it reduces risk factor of stress of many diseases. In contrast, the children under maintenance hemodialysis tend to live a hypoactive life and rarely participating physical activities. The reasons for their hypoactive life were justified by the presence of anemia which leads to exercise intolerance and easily fatigability⁽³⁵⁾.

In addition to renal osteodystrophy which is a significant problem for children with ESRD and osteomalacia or osteitisfibrosa reduction in bone mass or osteoporosis, these children don't usually complain of bone pain but often restrict their physical activities that protect a painful extremity^(29,30). The present study showed that 70% of studied children weren't practice exercises. This could be related to children's deficit of knowledge about the type of activities allowed, and they became easily fatigued as well as their parents gave them overprotection.

School age stage is a period of physical and emotional growth. In this stage, children are capable of assuming responsibility for their own need. They can also assume their share of household tasks and participate in different household activities. Such participation may contribute to children's maturation and it is important for expending their energy⁽²²⁾.

On the contrary, the present study showed that majority of studied children didn't practice home activities. These results could be related to overprotection from parents as they allow them not to share in home activities, which are reflected on children's psychological conditions and their dependency.

Regarding school activities, the current study revealed that the vast majority of studied children didn't practice any school. This result is justified by frequent school absenteeism of children and easy fatigability.

School is the workplace of children. It is the place for children to experience the increasing sense of competence. Renal failure and its care impose limits on children's physical and cognitive abilities and lead to irregular school attendance⁽²⁾. The present study showed that all studied children had an irregular attendance to school and a low achievement. This finding was explained by going the children to dialysis center to take dialysis session two or three days a week. Also, the school achievement is also affected.

Irregular school attendance and low achievement are supported by **Ragab** (1998), who mentioned that sick children with CRF under HI therapy were most properly liable to school disruption due to their absenteeism in addition to school failure and poor achievement. The main cause behind disruption of school attendance is repeated attendance to hospital (twice or thrice weekly for dialysis session). The lack of children concentration could be due to their illness, the socio economic factors and illiteracy of parent that also play a major role. **Delano** (1995), clarified that children with CRF had increased school absence which leads to social behavioral and learning problems^(2, 36).

With regard to children's spiritual attitudes **Brown** (2001), illustrated that the greater level of religiosity and spirituality are associated with fewer high-risk behaviors and more health promoting behaviors⁽³⁷⁾.

On contrary, the present study showed that the majority of studied children didn't practice religious obligations, didn't go to mosque/church frequently, so the majority of them weren't satisfied with their religious practices. These findings are justified by these children who are always fatigued, tired and frequently hospitalized reflect the presence of jealousy as these children were given much care and protection.

Chronic renal failure represents a major stressful event affecting all aspects of the children's lives, so sick children with CRF under maintenance hemodialysis need supports to make their families cope with their illness and overcome their physical, psychological and social problems through psychological motivations, providing diversional activities, maintain close contact relationship, providing efforts to enhance their school achievement as well as frequent recreational activities (TV, video tapes and local trips) and providing adequate health education regarding children's illness.

Conclusion:-

Based up on the results of study, it could be concluded that CRF as chronic illness, has many negative impact on physical, psychological, social and spiritual aspect of children's life. Generally their medical status is unpredictable and their life is disrupted, they often had financial problems sadness from a multiplicity of causes including, change in body image and dependency. Furthermore, their illness as well as HD therapy decreases their social and scholar activities within turn lead to frustration.

Recommendations:

- Nurses should encourage children's parents with maintenance hemodialysis to visit their relatives and improve social relations.
- Increasing the number of renal dialyses units to facilitate transportation of sick children with chronic renal failure.
- Nurses should cooperate with parent and school personals to encourage recreational activities and suitable hobbies. This can improve the psychological state of children.
- Individualized dietary counseling and nutritional education should be emphasized to help the child and his family to understand the needed requirement.

- Simple booklets or pamphlets containing explanation about the importance of nutrition and its necessary requirements for children with maintenance hemodialysis therapy that should be available in hospital.

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