Burden of Care among Family Caregivers of Children with Hemodialysis

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Abstract

Background: The children undergoing hemodialysis need caregiver support for several years which causes a high level of burden. Aim: Was to assess the burden of care among family caregivers of children undergoing hemodialysis. Design: A descriptive research design was utilized. Setting: The study was conducted at Pediatric hemodialysis unit at Benha University Hospital in Benha City and at Pediatric hemodialysis unit at Tanta University Student Hospital in Tanta City. Sample: A convenient sample which included 65 children with hemodialysis and their family caregivers. Tools: Tool I: A structured interview questionnaire which consisted of four parts to assess the socio-demographic characteristics, medical history, knowledge of the studied caregivers regarding hemodialysis and reported practices regarding care of their children with hemodialysis. Tool II: Pediatric Renal Caregiver Burden Scale (PR-CBS). Results: 47.7 % of the studied children aged from 12 to less than 18 years old and 58.5 % of them were female. 63.1% of the studied family caregivers aged from 30 to less than 40 years old, 70.8% of them were female and 93.8% of them were married. Conclusion: Less than one third of the studied family caregivers had good total knowledge of hemodialysis, more than half of them had satisfactory total reported practices regarding care of their children with hemodialysis. More than half of the studied family caregivers were in the high burden category. There was statistically significant correlation between the total knowledge score of the studied family caregivers, total reported practices score and total burden score. Recommendations: Educational programs should be developed and implemented for family caregivers to improve family caregivers' knowledge, practice and reduce burden of care for their children with hemodialysis.

Keywords: Burden of care, Hemodialysis, Family caregivers.

Introduction:

Renal failure and Chronic Kidney Disease (CKD) are important health issues for children under the age of eighteen years. In 2017, there were more than 30 children among every 100,000 suffering from CKD around the world. Statistically, 5-10% of children in the United States of America suffer from chronic kidney failure (Ammirati et al., 2020).

End Stage Renal Disease (ESRD) is defined as total loss of kidney function, it is a common problem worldwide, and it is diagnosed by several laboratory and imaging diagnostic procedures. It occurs when disease or condition impairs kidney function, causing kidney damage to worsen over several months or years. The goal of management of Chronic Renal Failure (CRF) in children is not only to prevent progression to ESRD but to fulfil the physiological and emotional needs of children to the best possible quality of life. It can achieve through early and appropriate treatment of reversible causes of CRF. It may help to achieve normal growth, development and periodic monitoring for rate of progression to ESRD to help plan for renal replacement therapy (Corsello et al., 2025).

Haemodialysis is the predominant approach to treat ESRD in children. Haemodialysis is a procedure used to cleanse blood and remove waste products like urea and creatinine from the blood. Dialysis is necessary when there is a significant fluid electrolyte imbalance, overload. hyperammonaemia, in children with kidney injury. congenital abnormalities of the kidney and urinary tract and glomerular disorders are common causes of pediatric kidney failure that require dialysis (Shroff et al., 2022).

Chronic haemodialysis has many complications as cardiovascular, nutritional, gastrointestinal, hepatic, endocrinal, nervous system, infections, complication related to vascular access devices. Children with haemodialysis are physically and mentally unable to provide the necessary treatment for themselves, require caregivers to assume major responsibility for their treatment whereas the burden of family caregivers leads to negative consequences not only for themselves but also for children, other family members, and health care system. Moreover, for caregivers, burden negatively affects caregiver's physical, emotional, and economic status (Bauer et al., 2021).

Family caregivers are usually one of the child's parents, family members, relatives or friends who should be in touch with patient for taking care of them without paid. They are the best source for caring the haemodialysis children as in personal hygiene, provision of medications, transfer of the child to the dialysis centre, assistance in eating food, emotional and mental support, and hospitalization. Caregiver may also be affected by physical and mental disorders due to the burden of care. The family caregivers are referred as "hidden patients" also, these factors can affect the quality of life of caregivers. The effect of caring role on the emotional, psychological, vitality and lifequality dimensions of these caregivers has been reported (**Rafati et al., 2020**).

Care burden is a distress or negative experience resulting from the provision of care, and includes financial, physical, social costs. Burden is definable and mental subjectively and objectively. Objective burden is defined as the changes and disruptions appear in life as a result of care. Subjective burden definition is the reaction or attitude of caregiver against care experience. Increased distress on caregivers will result in consequences such as family isolation, lack of hope for social support, disorders in family relations, anxiety, depression, isolation and inadequate care of the patient, eventually, the patient may give up the treatment. Generally, the demographic characteristics of caregivers, including gender, age, socio-economic status and so on can have an impact on the care burden (Salsabila et al., 2024).

Community Health Nurses (CHNs) play a key role in coordinating support services and resources to address the holistic needs of children with haemodialysis and their families. CHNs facilitate referrals to social workers. dietitians. mental health professionals and other support services to address emotional, psychosocial and practical concerns. Nurses also collaborate with community organizations, advocacy groups and educational institutions to connect families with resources and programs that promote health and well-being (Abebe et al., 2022).

Aim of study:

This study aimed to assess the burden of care among family caregivers of children with hemodialysis.

Research questions:

1-What is the knowledge of family caregivers regarding hemodialysis?

2-What are the reported practices of family caregivers regarding their children with hemodialysis?

3-What is the level of burden of care among the family caregivers of children with hemodialysis?

4-Is there a relation between caregiver's knowledge, practices and their burden of care?

Subjects and Method:

Research design:

Descriptive research design was utilized to conduct this study.

Study setting: This study was conducted at Pediatric hemodialysis unit at Benha University Hospital in Benha City and at Pediatric hemodialysis unit in Tanta University Student Hospital in Tanta City.

Study sample:

Convenience of all children and their family caregivers attended to the previously mentioned settings; they were be chosen according to inclusion criteria; Children undergoing haemodialysis aged under eighteen years and family caregivers who accepted to be involved in the study. Total number is 65 child and their family caregivers (32 child from Tanta Hospital and 33 from Benha Hospital)

Tools of data collection:

Two tools were used in this study:

Tool (1): Structured interviewing questionnaire was used in this study; It was developed by researchers based on reviewing the related literatures and written in simple Arabic language. It consisted of four parts:

First part:

A-Socio-demographic characteristics of the studied family caregivers. It included 9 close ended questions (age, sex, relatives, marital status, education level, residence, occupation, number of family members and income).

B-Personal data of the studied children it included 4 close ended questions (age, sex, ranking and education).

The second part: It was concerned with medical history and consisted of two parts:

- A-Medical history of the studied children with hemodialysis which included six close ended questions (onset of disease, duration of hemodialysis, number of hemodialysis sessions per week, number of hours for each session, chronic disease and medications).
- **B-** Medical history of the studied family caregivers which included four close ended questions (chronic diseases, genetic disease, medication and disability).

The third part: It was concerned with knowledge of the studied family caregivers regarding hemodialysis it included eleven questions as; Meaning of renal failure, causes of renal failure, symptoms of renal failure, diagnosis of renal failure, treatment methods of renal failure, complications of renal failure, number of hours for sessions per week, nutrition, care of fistula and central venous catheter, measures that help improve the child's condition and source of their information about hemodialysis.

Scoring system of knowledge:

The scoring system family of caregiver's knowledge was calculated as follows 2 score for complete and correct answer, while 1 score for incomplete and correct answer and 0 score for don't know the answer. For each question of knowledge, the score of the items was summed up and the total divided by the number of items. These scores were converted into a percent point and the total knowledge score was classified as the following: Total scores of knowledge was =22 points). Good when total score was >75%> (16 points) average when the total score was 50 - < 75% (11 points) while considered poor when the total score was <50% < (11)points)

The fourth part: It was concerned with reported practices of the studied family caregivers regarding the care of their children, which included 35 items divided into nine main items.

1-Pain relieving: which included 4 items as provide child pain relieving medications as doctor order, massage the site of pain, train on deep breathing exercises, visit the doctor and medical advice. 2-Fever: seek Which included 4 items as make cold compresses, give antipyretics, give the child plenty of fluids allowed, lighten the clothes of child. 3-Infection: Which included 4 items as give the child healthy food, take care of central catheter and the fistula, clean the environment surrounding the child, notice signs of inflammation and infection and inform the doctor. 4-Care of fistula and central venous catheter: Which included 3 items as; take care of its cleanliness on a regular basis, prevent child from carrying heavy objects, do not measure the pressure from the arm of the fistula. 5-Giving medications at home: Which included 4 items such as, avoid touching medications with hands, give the prescribed medications to the child regularly, keep dangerous medications out of reach of the child, follow the validity and expiry date of medications. 6-Muscle tension: Which included 4 items such as massage the tension working site and muscle lengthening exercises, inform the doctor responsible for the child, use hot or cold compresses for tense muscles, encourage the child to exercise sports.

7- School narratives and going to school: Which included 4 items such as help the child in solving problems in the area with school narratives, follow up the academic level of the child, help the child in organizing time between studying, rest and going to hemodialysis sessions. 8-Nutritional practices: Which included 4 items such as limitation of food high in phosphorus and potassium, limitation of protein and calcium, ban canned food and fast food, regulate the daily fluid intake of the child. **9- Stress and Fear:** Which included 4 items such as encourage the child to say what he feels, tell the child who is always by his side to protect him, encourage the child to interact with others, stay away from my child for short periods of time so he can rely on himself. **Scoring system:**

The scoring system for family caregivers reported practices was calculated as follows 2 score for always done 1 score for sometimes done while 0 score for never done. The score of each question of reported practices was summed- up and the total is divided by the number of items. These scores were converted into a percent score and the total reported practice score was classified as follows:

Total scores of reported practices was =70 points and considered satisfactory if the score of the total reported practices was $\geq 60\% \geq 42$ points, while considered unsatisfactory if the score of the total reported practices was< 60 % <42points.

Tool 11: Pediatric Renal Caregiver Burden Scale (PR-CBS): scale to measure the family caregiver's burden included 51 items was adapted from (**Parham et al., 2016**). The questionnaire was measured on a three Likert scale (Always, Sometimes and Never) which consisted of eight parts physical, financial, social, emotional, caregiver role/identity, impact on family, impact on child, chronic kidney disease treatment and contact with team.

Scoring system:

Burden scale score was calculated as 2 scores for always, 1 scores for sometimes and 0 for never. The total burden score was =102 points and considered high if the score was \geq 75% (\geq 76 points), considered moderate if the score was between 50-<75% (51-76 points), and considered low if the score was<50% (<51points).

Validity of tools:

Content validity of the tool was ascertained by five of Faculty Staff Nursing Experts from the Community Health Nursing Specialists (five from faculty of Nursing Benha University) who reviewed the tool for clarity, relevance, comprehensiveness, applicability, implementation and according their opinion minor modifications were done. **Reliability of tools:**

Reliability of the tools was applied by the researchers for testing internal consistency of the tools, by administration of the same tools to the same subject under similar condition on one or more occasion. The reliability of the tools was done by Cornbrash's Alpha coefficient test which revealed that each of the two tools consisted of relatively homogeneous items as indicated by the moderate to high reliability of each tool. The internal Reliability for knowledge =0.76. Reliability for practices =0.826. Reliability for Burden=0.704

Ethical consideration:

Ethical approval was obtained from the Scientific Research Ethical Committee at the Faculty of Nursing at Benha University before starting the study. All ethical issues were assured; Oral consent has been obtained caregivers of children before conducting the interview and given them a brief orientation to the purpose of the study. They were also reassured that all information gathered would be treated confidentiality and used only for the purpose of study at any time without giving any reasons. The study didn't show any physical, social, or psychological risks. Ethics, values, and cultures were respected.

Pilot study:

The pilot study was carried out on 6 caregivers who represented 10% of total sample size. The pilot was aimed to assess the validity, clarity, applicability of tools and time needed was 30-45 minutes to fill each

sheet as well as to identify any obstacles that may hinder the data collection. The pilot study was included in the total sample as no modifications were done.

Procedure for data collection:

Preparation of the study design and data collection tools were based on review of the current and past available national and international references related to the research title was done, using journal, textbooks and internet search was done. This was necessary for the researchers to be acquainted with and oriented about aspects of the research problem as well as to assist in the development of data collection tools: this takes time for preparing the tools about two months

Field work:

Data were collected at a period of six months which started from the beginning of February 2024 to the end of July 2024. The researchers introduced themselves and explained the aim of the study to each subject, collection were done through data interviewing with the caregivers. Data collection was done at Benha University Hospital in Benha City and at pediatric haemodialysis unit at Tanta University Students Hospital in Tanta City. average number of caregivers was between 4-5 caregivers a day depending on the responses. The average time needed to fill tools for each caregiver was around 30-45 minutes. The researchers visited the selected unites from 8 am to 12 bm 2 days/week to collect data.

Statistical analysis:

All data were organized, categorized, tabulated and analysed by using Statistical Package for Social Science (SPSS) version 22, which was used frequencies and percentage for qualitative descriptive data and chi square was used for quantitative data. Data were presented by using proper statistical tests that were used to determine whether there was significant relation or not and if there were positive correlation or not. P-value was used to determine significance of results as follows:

• P value >0.01 is no statistically significant difference.

• P value <0.05* is statistically significant difference.

• P value <0.001** is highly statistically significant difference.

Results:

Table (1) show that 63.1% of the studied family caregivers aged from 30 to less than 40 years old with mean age was 38.78 ± 6.99 . 70.8% of the studied family caregivers were female, 93.8% were married, 60.0 of them had secondary education, 89.2% of them were living in rural areas and 87.6% didn't work. As well as 63.1% of studied caregivers had enough income and 87.6% of them had 3-5 family members.

Table (2) shows that 47.7 % of the studied children aged from 12 to less than 18 years old with mean age 11.27 ± 3.73 years old and 58.5 % of them were female. Regarding child arrangement, 43.1% of the studied children were the middle in ranking and 70.8 % of them had basic education.

Figure (1) illustrates that, 30.8% of the studied family caregivers had good total

knowledge regarding hemodialysis, while 49.2 % of them had average total knowledge and only 20 % of them had poor total knowledge regarding hemodialysis.

Figure (2) demonstrates that, 58.5% of studied family caregivers had satisfactory total reported practices regarding care of their children with hemodialysis and 41.5% of them had unsatisfactory total reported practices regarding care of their children with hemodialysis.

Table (3) shows that, 84.6% of the studied family caregivers had high financial burden, caregiver role\identity, 83.1% of them had high burden regarding communication with hospital \medical staff, 81.5% of them had high emotional burden, while 35.4% of them had moderate burden regarding influence on the family, 32.3% of them had moderate burden regarding influence on the child and 16.9% of them had low physical burden and burden regarding responsibilities of treating chronic kidney disease.

Table (4) shows that, there were statistically significant correlation between total knowledge score of studied family caregivers, their total reported practices score and their total burden score (p<0.05).

Socio demographic	No.	%						
characteristics								
Age/years								
30>-40	41	63.1						
40>-50	21	32.3						
>50	3	4.6						
Min – Max 29-70								
Mean ±SD 38.78±6.99								
Sex								
Male	19	29.2						
Female	46	70.8						
Relativeness								
First degree	63	96.9						
Third degree	2	3.1						
Marital-status	Marital-status							
Married	61	93.8						
Divorced	2	3.1						
Widowed	2	3.1						
Education level								
Can not read and write	8	12.3						
Basic education	11	16.9						
Secondary education	39	60.0						
High education	7	10.8						
Occupation	· ·							
Not working	57	87.6						
Employee	4	6.2						
Freelancing	4	6.2						
Residence	· ·							
Rural	58	89.2						
Urban	7	10.8						
Income								
Enough	41	63.1						
Not enough	24	36.9						
Family number								
1-3	4	6.2						
3-5	57	87.6						
>5	4	6.2						

Table (1): Distribution of studied family caregivers regarding their socio demographic characteristics (n=65)

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Personal data	No.	%						
Age								
1>6 Years	6	9.2						
6>12Year	28	43.1						
12:18Years	31	47.7						
	Min-Max 4-17							
Mean ±SD 11.27±3.73								
Gender								
Male	27	41.5						
Female	38	58.5						
Ranking of child in his family								
The only one	5	7.7						
The first	21	32.3						
The middle	28	43.1						
The last	11	16.9						
Education								
Can not read and write	6	9.2						
Basic education	46	70.8						
Secondary education	13	20.0						



Figure (1): Percentage distribution of studied family caregivers regarding their total knowledge level about hemodialysis (n=65).



Figure (2): Percentage distribution of studied family caregivers regarding their total reported practices about hemodialysis (n=65).

Table (3):	Distribution	of studied	family	caregivers	regarding	their le	vel of b	urden ((n=65).
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Items	No.	%	No.	%	No.	%
Physical burden	43	66.2	11	16.9	11	16.9
Financial burden	55	84.6	10	15.4	0	0.0
Social burden	45	69.2	10	15.4	10	15.4
Emotional burden	53	81.5	12	18.5	0	0.0
Caregiver role\identity	55	84.6	10	15.4	0	0.0
Influence on the family	32	49.2	23	35.4	10	15.4
Influence on the child	44	67.7	21	32.3	0	0.0
Responsibilities of treating	43	66.2	11	16.9	11	16.9
chronic kidney disease						
Communication-with	54	83.1	11	16.9	0	0.0
hospital\medical staff						







		Total knowledge	Total practices	Total burden
Total knowledge	r	1	.732	563
	p-value		.011*	.073
	n	65	65	65
Total practices	r	.732	1	.256
	p-value	.011*		.040*
	n	65	65	65
Total burden	r	563	.256	1
	p-value	.073	.040*	
	n	65	65	65

Table (4): Correlation matrix between total knowledge, total practices and total burden (n=65).

Discussion:

The children undergoing haemodialysis need caregiver support; most often, this is given by the informal support system comprised of family members who become family caregivers for several years. Family caregivers fulfil most of the patient's physical, emotional, financial and social care needs throughout the continuum of care, from being hospitalised to providing care at home, without incentives. This study aimed to assess the burden of care among family caregivers of children with haemodialysis (Lasanthika et al., 2024).

Regarding to socio-demographic characteristics of studied family caregivers, the present study clarified that slightly less than two third of the studied family caregiver's aged from 30 to less than 40 years old with mean age was 38.78±6.99. This result agreed with Guha et al., (2022) who studied "Perspectives of Caregivers on Access to Health Care for Children with CKD" across five pediatric kidney units in Australia (n=32) and revealed that, mean age of studied family caregivers was 36.4 ± 6.9 . Also, this result agreed with Abebe et al., (2022), who studied "The lived experience of primary family of patients on haemodialysis caregivers treatment in Southern Ethiopia: а

phenomenological study" and demonstrated that the mean age of family caregivers was 35.4 ± 6.4 . On the other hand, this result was disagreed with the study performed by **Jardim et al., (2023)** who examined the study about "Quality of life of family caregivers of patients under haemodialysis" at Santa Casa and Hospital das Clínicas in Belo Horizonte, Minas Gerais, Brazil, (n= 75) and clarified that the mean age of the family caregiver was 50.0 ± 13.7 .

The present study clarified that more than two third of them were female and less than two third of them had secondary education, this result agreed with **Salsabila et al., (2024),** who studied "The Overview of Caregiver Burden in Families with Haemodialysis Patient" in Indonesia (n=107) and clarified that about two thirds of the participants were female and less than half of them had high school.

The finding of the present study showed that the most of studied caregivers were from rural areas, this result was inconsistent with **Sajadi et al., (2021),** who conducted study about "Investigating the relationship between quality of life and hope in family caregivers of haemodialysis patients and related factors" in Iran n=300 and showed that slightly less than two thirds of the participants were from urban areas.

The present study clarified that the majority did not work and less than two thirds of them had enough income. This result agreed with Ebadi et al., (2021) who studied "Psychological consequences for family caregivers of patients receiving haemodialysis: threat or opportunity?" in Tehran, Iran, (n=19) and demonstrated that less than two third of the participants weren't working and more than half of them had inadequate income. On the other hand, this result disagreed with Jardim et al., (2023), who revealed that less than one quarter of the participants weren't working and less than half had enough income.

Concerning personal data of studied children, the current study demonstrated that; less than half of the studied children aged from 12 to less than 18 years old with mean age 11.27 \pm 3.73 years old and about three fifth of them were female. This result supported by **Ebadi et al., (2021)**, who reported that 56.3% of the participants were female. However, this result disagreed with **Guha et al., (2022)** who mentioned that mean age of children was 8.3 \pm 4.1. Also, this result was inconsistent with **Salsabila et al., (2024).** who revealed that, only 1% of the patients aged from 12 to less than 18 years old.

As regards to total practices level of studied family caregivers, the present study findings represented that about three fifth of studied family caregivers had satisfactory total reported practices regarding care of their children with haemodialysis and less than half of them had unsatisfactory total reported practices regarding care of their children with haemodialysis. This finding disagreed with **Sousa et al., (2023)** who studied "Designing family-based interventions in kidney failure: The perspectives of the triad 'patients on haemodialysis/family caregivers/healthcare professionals" at two dialysis units (n=82) and revealed that half of studied family caregivers had satisfactory total reported practices regarding care of their patient with haemodialysis.

In relation to distribution of studied caregivers regarding their level of family burden, the current study demonstrated that the majority of the studied family caregivers high financial burden, had caregiver role\identity, as well as burden regarding communication with hospital \medical staff and emotional burden, more than two thirds of them had high social burden, while slightly more than one third of them had moderate burden regarding influence on the family and burden regarding influence on the child, minority of them had low physical burden and burden regarding responsibilities of treating chronic kidney disease. This result agreed with Bauer et al., (2021), who showed that among all caregivers, the domains with the highest frequency of burden was financial burden, with 71% of caregivers reporting that this is at least sometimes a problem. However, this result disagreed with Pio et al., (2022), who studied "Assessing burden, anxiety, depression, and quality of life among caregivers of haemodialysis patients in Indonesia: A cross-sectional study" and revealed that 52.9% of the participants had little or no burden.

Concerning correlation between total knowledge, total practices and total burden, the current study clarified that there was statistically significant correlation between total knowledge score of studied family caregivers, total reported practices score and their total burden score (p<0.05).

From researchers' point of view, caregivers with higher knowledge scores are better equipped to implement proper caregiving practices, as they understand the reasoning and methods behind recommended actions. While proper practices can enhance care quality, they may also increase the caregiver's workload and responsibilities, contributing to feelings of burden. Also, higher knowledge levels can alleviate stress by reducing uncertainty and enabling caregivers to feel more in control of their child's care.

Conclusion:

Less than one third of the studied family caregivers had good total knowledge regarding haemodialysis, more than half of them had satisfactory total reported practices regarding care of their children with haemodialysis. More than half of the studied family caregivers were in the high burden category. There was statistically significant correlation between total knowledge score of studied family caregivers, total reported practices score and their total burden score

Recommendations:

1-Providing hemodialysis children and their family caregivers with empowerment programs which include effective health education that contain knowledge about hemodialysis, healthy nutrition, fistula care and psychosocial and spiritual support for children and families to improve their quality of life.

2- Dialysis centers should be prepared to meet the amusement and entertainment needs of children, aligning with their age group to make dialysis sessions more pleasurable and comfortable.

3- Further studies should be performed to devise specialized programs aimed at decreasing and managing stress and anxiety and improving quality of life.

References:

Abebe, A., Arba, A., Paulos, K., Abera, W.,Sidamo, T., Shiferaw, S., andWoldeyohannes, S. (2022). The livedexperience of primary family caregivers of

patients on hemodialysis treatment in Southern Ethiopia: a phenomenological study. International Journal of Nephrology and Renovascular Disease, 41-52.

Ammirati, L. (2020). Chronic kidney disease. Revista da Associação Médica Brasileira, 66, s03-s09.

Bauer, A., Blanchette, E., Taylor, C., and Wightman, A. (2021). Caregiver burden in pediatric dialysis: application of the Pediatric Renal Caregiver Burden Scale. Pediatric Nephrology, 36(12), 3945-3951.

Corsello, A., Trovato, M., Dipasquale, V., Proverbio, E., Milani, P., Diamanti, A., and Romano, C. (2025). Malnutrition management in children with chronic kidney disease. Pediatric Nephrology, 40(1), 15-24.

Guha, C., Khalid, R., Mallitt, K. A., van Zwieten, A., Francis, A., Kim, S., and McTaggart, S. (2022). Perspectives of Caregivers on Access to Health Care for Children with CKD. Kidney International Reports, 9(11), 3177-3189.

Ebadi, A., Sajadi, A., Moradian, T., and Akbari, R. (2021). Psychological consequences for family caregivers of patients receiving hemodialysis: threat or opportunity?. BMC psychology, 9, 1-7.

Jardim, R., Reis, A., Amaral, A., & and Torres, C. (2023). Quality of life of family caregivers of patients under hemodialysis. Acta Paulista de Enfermagem, 36, eAPE00372.

Lasanthika, C., Janlöv, A. C., Amarasekara, T., and Larsson, H. (2024). Caring burden and coping with haemodialysis: a qualitative study with family caregivers in Sri Lanka. BMJ open, 14(4), e080775.

Parham R, Jacyna N, Hothi D, Marks SD,Holttum S, andCamic P (2016).Development of a measure of caregiverburden in paediatric chronic kidney disease:

the Paediatric Renal Caregiver Burden Scale. J Health Psychol 21:193–205

Pio, T., Prihanto, B., Jahan, Y., Hirose, N., Kazawa, K., and Moriyama, M. (2022). Assessing Burden, Anxiety, Depression, and Quality of Life among Caregivers of Hemodialysis Patients in Indonesia: A Cross-Sectional Study. International Journal of Environmental Research and Public Health, 19(8), 4544.

Rafati, F., Mashayekhi, F., and Dastyar, N. (2020). Caregiver burden and spiritual wellbeing in caregivers of hemodialysis patients. Journal of religion and health, 59(6), 3084-3096.

Sajadi, A., Farsi, Z., Akbari, R., Sadeghi, A., and Akbarzadeh Pasha, A. (2021). Investigating the relationship between quality of life and hope in family caregivers of hemodialysis patients and related factors. BMC nephrology, 22, 1-10. Salsabila, N., Pratiwi, H., and Emaliyawati, E. (2024). The Overview of Caregiver Burden in Families with Hemodialysis Patient. Indonesian Journal of Global Health Research, 6(3), 123.

Shroff, R., Hothi, D., and Symons, J. (2022). Chronic hemodialysis in children. In Pediatric nephrology (pp. 1835-1868). Cham: Springer International Publishing.

Sousa, H., Ribeiro, O., Christensen, J., and Figueiredo, D. (2023). Designing familybased interventions in kidney failure: The perspectives of the triad 'patients on haemodialysis/family caregivers/healthcare professionals. British Journal of Health Psychology, 28(3), 672-689.



عبء الرعاية بين مقدمي الرعاية الأسرية لأطفال غسيل الكلى الدموي

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يحتاج اطفال غسيل الكلي الي الدعم من مقدمي الرعايه وعادة ما يكون مقدمي الرعاية الأسرية أحد والدي الطفل أو أفراد الأسرة أو الأقارب أو الأصدقاء الذين يجب أن يكونوا على اتصال بالمرضي لرعايتهم دون مقابل. و قد يتأثر مقدمي الرعاية الأسرية أيضًا باضطر ابات جسدية وعقلية ونفسية بسبب عبء الرعاية. ويعرف عبء الرعاية بانه تجربة ضائقة أو سلبية ناتجة عن تقديم الرعاية، ويشمل التكاليف المالية والجسدية والاجتماعية والعقلية. لذا هدفت هذه الدراسة الي تقييم عبء الرعاية بين مقدمي الرعاية الأسرية لأطفال غسيل الكلى الدموي. وقم تم استخدام تصيم وصفي لاجراء الدراسه في وحده الغسيل الكلوي للاطفال بمستشفي جامعه بنها في مدينه بنها ووحده استخدام تصيم وصفي لاجراء الدراسه في وحده الغسيل الكلوي للاطفال بمستشفي جامعه بنها في مدينه بنها ووحده الغسيل الكلوي للاطفال بمستشفي الاطفال جامعه طنطا في مدينه طنطا. وشملت الدراسه جميع الحالات المتوفره ان ٨, ٣٠٪ من مقدمي الرعايه كانت لديهم معلومات جيده بالغسيل الكلوي. ٥, ٥ اظهر وا ممار سات مرضيه تنها ورحده رعايه الطفال، كما كان ٨, ٣٠٪ منهم لديهم معلومات جيده بالغسيل الكلوي. ٥, ٥ اظهر وا ممار سات مرضيه تعايم النتائج رعايه الاطفال، كما كان ٨, ٣٠٪ منهم لديهم معلومات جيده بالغسيل الكلوي. العباد والمار الراحية مرضية تنه المالية منه منو على من العرار ما من الراحية مرضية مرضيه ترامع موال مقدمي الرعايه لتصين معلوماتهم وممار ستهم في رعايه الاطفال الذين يخضعون للغسيل الكلوي .

