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KNOWLEDGE & SATISFACTION OF CAREGIVER OF CHILDREN WITH ENDOCRINE DISEASES ATTENDING SOME ENDOCRINE CENTERS IN BAGHDAD, 2025

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ABSTRACT

Background: A comprehensive Knowledge & Attitude assessment can identify the lack of disorder related knowledge, misconceptions that lead to non-adherence, and psychosocial barriers to high quality care. **Objectives:** Assess knowledge & Satisfaction of Caregiver of Children with Endocrine Diseases Attending Some Endocrine Centers in Baghdad also, Find the association of caregivers' overall satisfaction with their and their children demographic variables. **Method & subjects:** A cross-section study with analytic elements, conducted in 2025, by interviewing the caregiver of the children attending 3 Specialized endocrinology and diabetes centers in Baghdad city. **Results:** caregivers enrolled were 364, of child with diabetes mellitus 157(43.1 %), of child with growth hormone diseases121(33.2%), while 86(23.6 %) of child with thyroid diseases, the children age with mean & standard dev. (9.98 ± 3.013), participants mostly 293(80.5%) had good-satisfaction about the endocrine center, Health education received in the endocrine centers helped in giving-treatment 225(61.8 %), food and nutrition 196(53.8 %), sleeping and sports in 87(23.9 %), also regular health-visiting 54(14.3 %), and psychological-health 9(2.5%). the endocrine centre 346(95.1%) is the main information-source, there is a significant association between the caregiver overall-satisfaction and their Job, Child-relation, and educational-level ($P\text{-value} \leq 0.05$), opposite to age, marital-status of the child 's parents, residency, and Family month-income. **Conclusion:** caregivers had high levels of satisfaction with healthcare service. despite this favorable perception, caregivers` self-rated knowledge regarding their child`s condition remained mostly neutral to poor.

KEYWORDS: Knowledge, satisfaction, diabetes-mellitus, congenital-hypothyroidism, growth- hormone deficiency Baghdad, Iraq.

INTRODUCTION

Family home has been slowly gaining control on pediatric endocrinology chronic care in Type 1 Diabetes Mellitus (T1DM), Congenital Hypothyroidism (CH), and Growth Hormone Deficiency (GHD).[1- 3] These diseases demand the patient to undergo elaborate treatment plans throughout his or her entire life, such as mandatory hormone replacement therapy, continuously monitoring of the level of glucose in his or her blood, as well as careful calculations of food and injections intake, all of which play significant roles in the maintenance of metabolic balance and the avoidance of complications.[4]

In this system, parents and primary caregivers turn into de facto professionals in healthcare and are at the center of the process, regarding the daily treatment programs and the physiological balance realization in their child. In this regard, knowledge is the understanding of the etiology of diseases, the rationale of treatment, and potential complications.[5-7]

Attitude includes the perceived severity and vulnerability of the condition, perceived advantages and obstacles to management, and emotional acceptance of the diagnosis.[8-10]

Such domains are opposing to established models of chronic diseases, in which knowledge gaps or negative attitudes directly impact the outcome, including high-risk glycemic variability in T1DM, poor neurodevelopment in CH, or ineffective linear growth in GHD.[11-15]

Despite the fact that there is one commonality between these disorders, i.e., hormonal deficiency, which requires supplementing, they present peculiar challenges to the caregiver.[16]

T1DM management is a hectic and acute process, which involves making decisions on a daily basis and actively with regard to food, activity, & stress, this could lead to high rates of caregiver burnout and anxiety.[17] The insistence of the newborn screening follow-up being crucial and the simplicity of the replacement with levothyroxine over the course of the life of a patient can be called into question in regards to the misconceptions regarding the premise that the disease is curable or minor in CH.[18]

GHD therapies are given as a daily injection into the subcutaneous area, and this makes a patient burdened in terms of needle phobia, cosmetic appearance, and the psychological stress of having a disease that cannot receive metabolic feedback instantly, like in diabetes.

The assessment of the Knowledge, Attitudes, and Practices (KAP) of parents facing this heterogeneous topography is not only a major public health concern, but also not an academic endeavor either. A comprehensive KAP assessment can identify the lack of disorder related knowledge, misconceptions that lead to non- adherence, and psychosocial barriers to high quality care.[19- 22]

Last but not least, parents should be empowered with the knowledge of right, positive attitudes, and enable them acquire sustainable best practices. All of these steps would be important to the achievement of target biomarkers (e.g., HbA1c, TSH, IGF -1) and the quality of life of the child and family unit, which, in turn, would be essential to enable the success of transferring the responsibility of care to the adolescent patient in the future.[23,24]

The aim of this study will be to compare and contrast parental knowledge and attitudes associated with T1DM, CH, and GHD critically to come up with evidence on the application of effective family entered care approaches in pediatric endocrinology.

OBJECTIVES

1- Assess knowledge of Caregiver of Children with Endocrine Diseases Attending Some Endocrine Centers in Baghdad
2- Assess Satisfaction of Caregiver of Children with Endocrine Diseases Attending these Endocrine Centers.
3- Find the association of caregivers' overall satisfaction with some of their and their children demographic variables.

METHOD AND SUBJECTS

Study Design

A cross-sectional study with analytic elements, conducted from 1st Sep. 2025 – 15th Sep. 2025, by interviewing the parents and caregiver of the children attending 3 Specialized endocrinology and diabetes centers in Baghdad city (Specialized endocrinology and diabetes center in al-Kindy teaching hospital, Kadhimiya hospital for children /endocrinology department, and Central teaching hospital of pediatrics/ endocrinology department).

Ethical approval: Subsequent to obtaining ethical and scientific permission from the Ministry of Health in Iraq, as well as from other centers and hospitals. The study was executed in complete adherence to established ethical norms. Informed consent was acquired from the caregivers before performing in-person interviews. Verbal consent was obtained, and a notation was incorporated into all data collection forms highlighting the study's importance, the voluntary aspect of participation, and the guarantee of secrecy about participant information.

STUDY POPULATION

Included criteria: all the parents or caregivers of child with major endocrine disease or disorders (diabetes mellites, growth hormone disease, thyroid hormone disease) attending the choosing centers at the day of visiting day. By taking a verbal consent to enrolled in this study by interviewing.

Excluded criteria

1. Any parent who refuses to involve in this study
2. Any parents or caregivers of child with other endocrine disease or order.

The questionnaire

It's developed by the authors after reviewing many literatures, It consists of **three domains**: **first domain** is consists of "demographic variable of caregiver of child with major endocrine disease or disorders: caregiver age, job, educational level, marital status, child relation, residency, siblings, family monthly income, diagnosis date, first time heard about your child disease, type of the endocrine disease or disorder, age of the child with major endocrine disease or disorders). **Second domain** is about satisfaction consists from two parts: first is about of care giver about health services: (lab. services, drugs supplements, worker behavior, doctors' behavior, worker performances, doctors' performances) & also second part consists from six questions: "overall satisfaction about your child endocrine center", "Unsatisfied Couse", "Have you previously filed a complaint about those reasons", "Did they fix it", "Did you advise others about this center". **Third domain** consists of five questions: (knowledge Perception, Source of information, The most trustable source about child disease, Has the source of your information about child illness helped you in the following: Giving treatment, Food and nutrition, Sleeping and sports, Regular health visiting, psychological health). Scaling their knowledge according to their perception with 10 degrees (1 very poor, 10 very good).

The scoring of the overall satisfaction

There are six questions answered with
(1= strongly disagreed, 2 = disagreed, 3 = neutral, 4 = agreed, 5 = strongly agreed)

Poor overall satisfaction	(6 – 14)
Accepted overall satisfaction	(15 – 22)
Good overall satisfaction	(23 – 30)

Sampling technique

The parents or carers of a child with significant endocrine diseases or disorders (such as diabetes mellitus, growth hormone deficiency, or thyroid hormone problems) who are attending the designated centres on visitation days (twice a week for six months).

Statistical analysis

The data was conducted utilizing SPSS version 26. Frequency, percentage, and Chi-Square test were employed. P < 0.05 was considered significance.

RESULTS

Three hundred & sixty-four (364) caregivers enrolled in this study, aged the highest percentage 244(67.0%) aged (30-39 years old, with Mean & SD = 40.74 ± 10.227, after 179(49.2%) as housewives, followed by 73(20.1%) as owner, the highest percent 136(37.4%) were complete primary as educational level, child mothers 198(54.4 %), Resident in urban 344(94.5 %), the child has 1-3 siblings 195(53.6 %), 165(45.3 %) of the Family have month income between 1.5 million -2million, the Child diagnosed within 1 y - less than 2 year.

When the caregiver asked about first time heard about his child disease, 193(53.0 %) of them heard before child diagnosis, while 171(47.0 %), heard about the disease at & after child diagnosis, all shown in table (1).

Table (1): Distribution of the participants according to their demographic variables & child disease features.

		Frequency	**Percent**
Total		364	100.0
Caregiver age Mean & SD = 40.74 ± 10.227	≥ 29 years	51	14.0
	30-39 years	**244**	**67.0**
	50-59years	69	19.0
Job	gov. employee	65	17.9
	non-gov. employee	16	4.4
	owner	73	20.1
	retired	7	1.9
	housewife	**179**	**49.2**
	student	10	2.7
	unemployed	14	3.8
Educational level	not read/not write	25	6.9
	complete primary	**136**	**37.4**
	complete secondary	98	26.9
	complete institution	48	13.2
	complete college	45	12.4
	complete postgraduated	12	3.3
Marital status of the child 's parents	**life together**	**347**	**95.3**
	live separated	15	4.1
	one of parents died	2	0.5
Caregiver relation to the child	father	146	40.1
	mother	**198**	**54.4**
	grandmother and father	11	3.0
	relative	9	2.5
Residency	**urban**	**344**	**94.5**
	rural	20	5.5
Child's Siblings	his is only child	25	6.9
	1-3 child	**195**	**53.6**
	4 and above	144	39.6
Family month income	half million & lower	5	1.4
	>half million - million	7	1.9
	> million -1.5 million	28	7.7

	> 1.5 million -2million	**165**	**45.3**
	> 2 million and above	137	37.6
	I don't know	22	6.0
Diagnosis date	6 m and more	40	11.0
	6m - less than 1 year	80	22.0
	1 y - less than 2 year	**126**	**34.6**
	2 y & more	118	32.4
First time heard about your child disease	**before child diagnosis**	**193**	**53.0**
	at & after child diagnosis	171	47.0

The study found that the caregiver of 157(43.1 %) of child with diabetes mellites, 121(33.2%) of child with growth hormone diseases, while only 86(23.6 %) of child with thyroid diseases, the children age with mean &standard dev. (9.98 ± 3.013), as shown in figure (1) & (2).

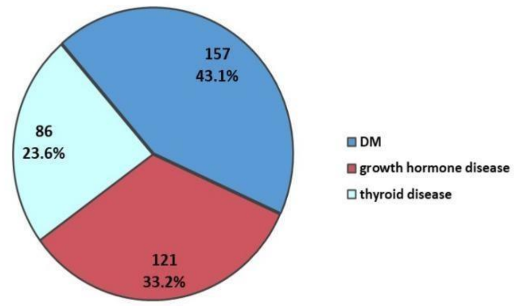

figure (1): Distribution of children according to their endocrine disease types (N = 364)

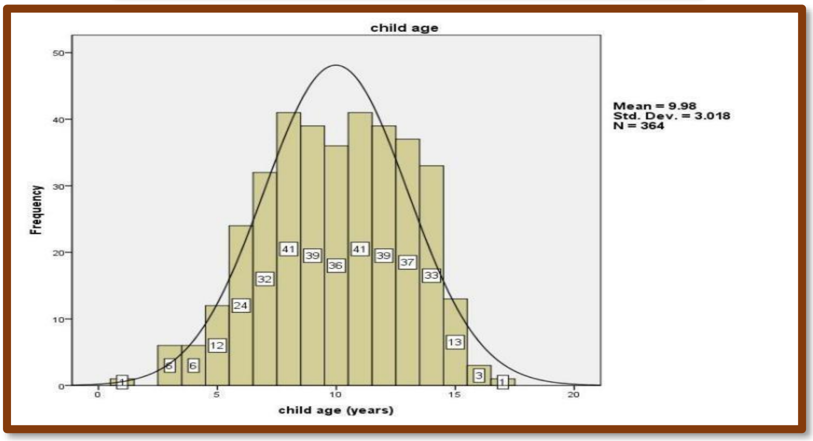

Fig. (2): Diseased children age distribution (N= 364).

When the caregiver asked about their satisfaction about health services provided in the endocrine centers, majority of the participants have well satisfied about Lab. Services 205(56.3%), drugs supplements 181(49.7%), worker behavior 238(65.4%), doctors behavior 241(66.2 %), worker performances 253(69.5%), and doctors performances 233(64.0 %). This is listed in table (2).

Table 2: Distribution of participants according to their satisfaction about health services provided in the endocrine centers.

	Excellent		Well		Accepted		Bad		Very bad	
	N	%	N	%	N	%	N	%	N	%
Lab. services	35	9.6	**205**	**56.3**	116	31.9	6	1.6	2	0.5
Drugs supplements	19	5.2	**181**	**49.7**	121	33.2	35	9.6	8	2.2
Worker behavior	53	14.6	**238**	**65.4**	70	19.2	3	.8	0	0
Doctors behavior	75	20.6	**241**	**66.2**	48	13.2	0	0	0	0
Worker performances	45	12.4	**253**	**69.5**	66	18.1	0	0	0	0
Doctors performances	94	25.8	**233**	**64.0**	37	10.2	0	0	0	0

Currents study revealed that the participants mostly 293(80.5%) had good satisfaction about the endocrine center, while remaining 71(19.5%) had accepted satisfaction, without poor satisfaction.

Drugs availability and continuity was unstable this mentioned by 44(12.1%) of the participants, Lab test availability and continuity also mentioned by 8(2.2%), while Bad recaption persons behavior mentioned only by 2(0.5%). Only 4(1.0%) only had previously filed a complaint about those reasons and one of these complain was fixed.

So, majority of the participants advise others about these endocrine centers 339(92.9%). It's according to table (3).

Table 3: Distribution of Participants According To Their Overall Satisfaction About Endocrine Center, Unsatisfied Cause, Compliant, Fixing The Problems And Advise Others About This Center.

		Frequency	Percent
Overall satisfaction about endocrine center	accepted	71	19.5
	good	293	80.5
Unsatisfied Couse	Drugs availability and continuity	44	12.1
	Lab test availability and continuity	8	2.2
	Bad recaption persons behavior	2	0.5
Have you previously filed a complaint about those reasons	already no complain	314	86.3
	No	46	12.6
	Yes	4	1.1
Did they fix it	No	3	0.8
	Yes	1	0.3
Did you advise others about this center	No	3	.8
	Yes, sometimes	23	6.3
	Yes, always	338	92.9

Neutral satisfaction 247(67.9 %) in caregivers about their Perception knowledge Endocrine center doctors was the most trustable source about child disease 299(82.1%). Health education received by the families of children in the endocrine centers helped them in giving treatment 225(61.8 %), helping in food and nutrition 196(53.8 %), sleeping and sports only in 87(23.9 %), also regular health visiting only 54(14.3 %), and psychological health 9(2.5%).

When asked about source of information (can choose more than one) the highest percentage was the endocrine centre 346(95.1%), followed by Private clinic doctors 253(69.5 %). As seen in table (4) & figure (3).

Table (4): Distribution of participants based on their Perception knowledge, the most trustable source about child disease, Health education helping in some aspects.

			Frequency	percent
Perception knowledge		Unsatisfied	53	14.6
		Neutral satisfaction	247	67.9
		Very satisfied	64	17.6
The most trustable source about child disease		Endocrine center doctors	299	82.1
		Private clinic doctors	46	12.6
		PHC doctors	2	.5
		Internet	15	4.1
		Family & friends	2	0.5
Health education in the endocrine center	Giving treatment	Helped me in	225	61.8
		Not helped	139	38.2
	Food and nutrition	Helped me in	196	53.8
		Not helped	168	46.2
	Sleeping and sports	Helped me in	87	23.9
		Not helped	277	76.1
	Regular health visiting	Helped me in	54	14.8
		Not helped	310	85.2
	psychological health	Helped me in	9	2.5
		Not helped	355	97.5

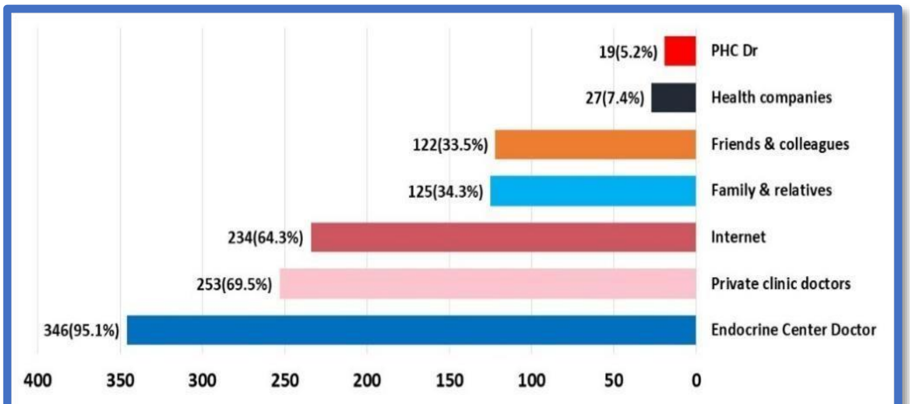

Fig. (3): source of information (more than of opition to be chosen)

According to what the participants feeling about their understanding the concept of their child disease, most of the answers were poor 154(42.3%), followed by neutral 128(35.2%) as shown in the figure (4), with neutral scale according to their perception (mean & SD =5.55 ± 1.999 out of 10) as appeared in figure (5)

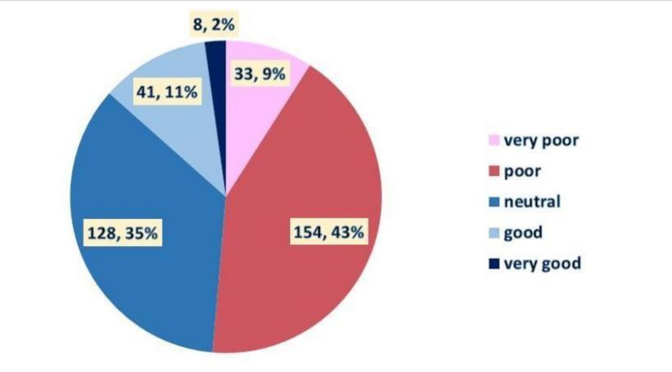

Fig (4): Distribution of the participants according to their understanding about their child's disease

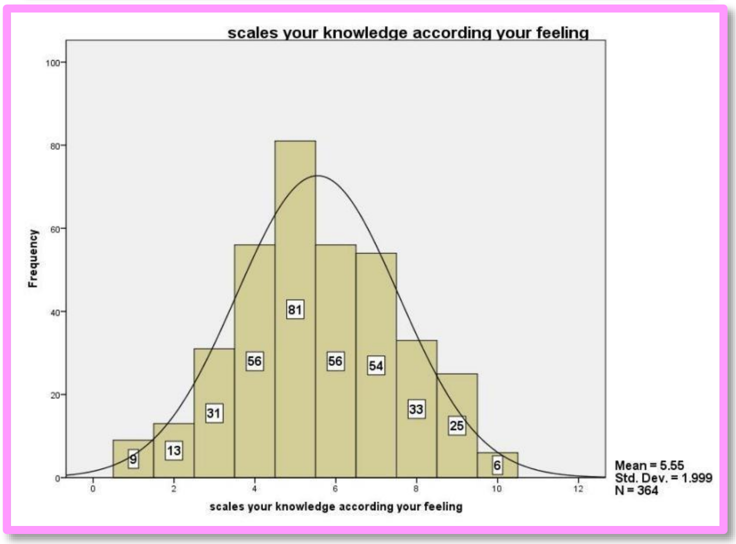

Figure 5: Scale the participants knowledge according to their feeling.

This study found a significant association between the caregiver overall satisfaction and their Job, Child relation, and educational level (p value = 0.002, 0.014, 0.001 correspondingly), but not with their age, Marital status of the child‘s parents, Caregiver relation to the child, residency, and Family month income. As seen in table (5).

Table 5: Association of caregivers' overall satisfaction with their and the child demographic variables.

		Overall satisfaction		Total	P value
		Accepted	Good		
Total		**71**	**293**	**364**	
Caregiver Age	≥ 29 years	4	47	51	0.057
	30-39 years	50	194	244	
	50-59years	17	52	69	
Job	Gov. employee	16	49	65	0.002
	Non-gov. employee	7	9	16	
	Owner	20	53	73	
	Retired	3	4	7	
	Housewife	24	155	179	
	Student	0	10	10	
	Unemployed	1	13	14	
Marital status of the child 's parents	Life together	65	282	347	0.099
	Live separated	6	9	15	
	One of parents died	0	2	2	
Caregiver relation to the child	Father	41	105	146	0.014
	Mother	29	169	198	
	Other Relative	1	19	20	
residency	Urban	70	274	344	0.092
	Rural	1	19	20	
siblings	His is only child	8	17	25	0.132
	1-3 child	32	163	195	
	4 and above	31	113	144	
Family month income	Half million & lower	2	3	5	0.589
	>Half million - million	1	6	7	
	> Million -1.5 million	3	25	28	
	> 1.5 million -2million	33	132	165	
	> 2 million and above	26	111	137	
	I don't know	6	16	22	
Educational level	Primary school & less	27	134	161	0.001
	complete secondary	11	87	98	
	complete institution	14	34	48	
	complete college	19	38	57	
Child age	> 10 yrs	28	133	161	0.335
	10 - > 15 yrs	40	146	186	

DISCUSSION

This cross-sectional study explored caregivers' knowledge and satisfaction regarding the management of major pediatric endocrine diseases (T1DM, GHD and thyroid diseases) in specialized endocrine centers in Baghdad.

Overall, a high level of satisfaction with healthcare services was observed with more than half of caregivers reporting good overall satisfaction. This reflects the central role of specialized endocrine centers as the primary source of information and care, consistent with international recommendations emphasizing multidisciplinary, family centered approaches in chronic pediatric endocrine disorders.[18-19]

Type 1 diabetes mellitus constituted the largest proportion of cases in this study, which aligns with global epidemiological data demonstrating the rising incidence of TIDM among children and adolescents.[3,31] caregivers of children with diabetes appeared more engaged in daily diseases management, likely due to the continuous demands of glucose monitoring, insulin administration, and dietary regulation. Previous studies have shown that parental knowledge and attitudes significantly influence glycemic control and reduce acute complications such as diabetic ketoacidosis.[18-19] This heightened vigilance, however, is often accompanied by increased caregiver anxiety and fear of hypoglycemia, which has been widely documented as a major psychosocial burden in families of children with T1DM.[19,34]

In contrast, caregivers of children with congenital-hypothyroidism demonstrated acceptable awareness of treatment necessity but limited understanding of long-term consequences of poor adherence. This finding mirrors reports indicating that the apparent simplicity of levothyroxine therapy and the absence of immediate symptoms may foster complacency over time.[27,30] longitudinal studies have emphasized that sustained parental engagement is essential to ensure optimal neurodevelopmental and growth outcomes in affected children.[30]

Growth hormone disorders represented one third of cases in the current study. Daily injections, concerns about height stigma, treatment costs, and uncertainty regarding prognosis create a complex decision-making environment for caregivers. Similar challenges have been described in international literature, where technical aspects of injections and psychosocial stressors frequently outweigh biomedical concerns in determining adherence to GH therapy.[1,16, 36] mothers` experiences of emotional strain and treatment fatigue have also been highlighted as key barriers to consistent administration.[36]

Although overall satisfaction with healthcare services was high, caregivers reported limited benefit of health education on psychological well-being and regular follow-up attendance. Only a small proportion perceived improvements in these domains, suggesting that current educational strategies may prioritize procedural instructions over holistic psychosocial support. This observation is agreed with evidence indicating that effective chronic disease management requires not only technical knowledge but also emotional coping strategies and behavioral reinforcement.[23,24]

Educational level, caregiver occupation, and relationship to the child were significantly associated with overall satisfaction. Higher educational attainment was linked to better satisfaction, likely reflecting improved health literacy and communication with healthcare providers. Similar associations have been reported in studies assessing parental engagement in pediatric endocrine care, where socioeconomic and educational factors strongly influence treatment adherence and health outcomes.[32,45]

Importantly, Physicians in endocrine centers were found to be the most reliable information source, highlighting the critical role that specialized teams play in influencing the attitudes and knowledge of carers. This research backs up global recommendations that structured education programs run by qualified multidisciplinary teams are the best way to improve outcomes for children with endocrine abnormalities.[18,19]

In the current study revealed that, despite high satisfaction rates, perceived knowledge levels remained largely neutral to poor, this discrepancy suggests that satisfaction with services does not necessarily translate into adequate disease understanding. Previous research has demonstrated that moderate parental knowledge is positively correlated with metabolic control and treatment adherence, highlighting the need for continuous, tailored education beyond routine clinical encounters.[45,46]

CONCLUSION

This study highlights that caregivers of children with major endocrine disease attending specialized centers in Baghdad generally reported high levels of satisfaction with healthcare service. However, despite this favorable perception, caregivers` self-rated knowledge regarding their child`s condition remained mostly neutral to poor. Type 1 diabetes mellitus represented the most common diagnosis, reflecting its growing burden among children.

The findings demonstrate that caregivers` educational level, occupation, and relationship to the child significantly influenced overall satisfaction, emphasizing the importance of socioeconomic and educational factors in shaping healthcare experiences. Although endocrine center physicians were identified as the primary and most trusted source of information, health education appeared to focus mainly on treatment and nutrition, with limited impact on psychological support, physical activity guidance, and regular follow-up behaviors.

These results underscore the critical role of caregiver knowledge and attitudes in the effective management of chronic pediatric endocrine disorders. Strengthening comprehensive, family-centered educational interventions is essential to improve long-term adherence, psychosocial well-being, and clinical outcomes for affected children.

Recommendation

1. Structured and continuous caregiver education programs should be implemented in endocrine centers, addressing not only treatment administration and nutrition but also psychological support, physical activity, and long-term disease complications.
2. Multidisciplinary care teams, including psychologists, dietitians, and specialized nurses, should be integrated into routine clinic visits to provide holistic support for families.
3. Educational materials should be simplified and tailored according to caregivers` educational levels to enhance understanding and retention of information.
4. Regular assessment of caregivers' knowledge and satisfaction should be incorporated into clinical practice to identify gaps early and guide individualized counseling.
5. Community-based awareness programs are recommended to improve early recognition of pediatric endocrine disorders and reduce misconceptions surrounding chronic hormonal diseases.
6. Future studies should adopt longitudinal designs to evaluate the impact of caregiver education on clinical outcomes such as glycemic control, growth parameters, and quality of life.

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