

Knowledge, Practice and Adjustment among Family Caregivers of Children Having Hearing Loss

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Abstract

Background: Providing care to children with hearing loss can be a difficult task for family caregivers, resulting in physical, emotional, and financial pressures. Informal caregivers require support to effectively sustain their role. **Aim:** This study aimed to assess knowledge, caregiving practices, and adjustment among family caregivers of children having hearing loss. **Design:** A quasi-experimental was used to achieve the aim of this study. **Setting:** The study was conducted in the outpatient Speech clinic affiliated with the faculty of Post Graduate Childhood Studies at Ain Shams University. **Subject:** A purposive sample of 40 family caregivers of children with hearing loss. **Tools of data collection:** 1) Demographic information was collected, as well as data from several scales, including the 2) Parent Knowledge Scale, 3) Family Caregivers' Reported Practices Questionnaire, and 4) Adjustment Scale. **Results:** The results of this study showed there was a significant difference in the knowledge, practice, and adjustment among family caregivers of children having hearing loss. **Conclusion:** The current study concluded positive impact on the knowledge, caregiving practices, and adjustment of family caregivers of children with hearing loss. **Recommendation:** The current study recommended that educational training programs among family caregivers of children having hearing loss to enhance knowledge, caregiving practices, and adjustment of family caregivers of children with hearing loss, as well as regular updates to ensure ongoing improvement in the knowledge, practices, and adjustment of family caregivers caring for children with hearing loss.

Keywords: knowledge, practice, adjustment, family caregivers, hearing loss

Introduction

The sensory experience plays a pivotal role in shaping the lives of all organisms, influencing them for granted, well-functioning senses contribute to a richer life. However, hearing loss, a prevalent sensory impairment, poses a significant challenge to this sensory richness (*Dammeyer et al., 2019*).

Hearing loss is defined as any impairment in the ability to hear sounds within normal thresholds. In children, deviations from the normative range are assessed through pure tone threshold averages. Deafness, often synonymous with profound hearing loss, signifies an inability to hear typical conversations without amplification. Those who experience mild to moderate hearing loss fall under the category of "hard of hearing" and often benefit from hearing aids (*Lieu, Kenna, Anne, and Davidson, 2020*). The global impact of hearing loss is staggering, with projections indicating that nearly 2.5 billion people will experience some degree of hearing loss by 2050. Disturbingly, 700 million,

their perception of the world and interaction with their surroundings. Often take

or one in every ten individuals, will grapple with disabling hearing loss, necessitating hearing rehabilitation. Alarming trends in unsafe listening practices place over 1 billion young adults at risk of permanent hearing loss. Furthermore, 430 million adults and 34 million children worldwide require rehabilitation for disabling hearing loss (*WHO, 2023*).

In Egypt, a national survey revealed that hearing impairment affects 16.0% of the population, totaling more than 13 million individuals across all age groups. Notably, children up to four years old exhibit a higher prevalence of 22.4%. Another study focused on Shebin El-Kom district reported a 20.9% prevalence of hearing loss among primary-school children (*Morgan et al., 2021*).

Hearing serves as a vital link, connecting individuals through speech, emotional sounds, and the appreciation of music. It heightens

awareness of the environment, providing warnings of potential dangers. The inability to hear profoundly influences how individuals connect with their surroundings, impacting lives across all age groups, especially when hearing loss is present from birth. Despite the awareness of hearing loss, its widespread impact tends to be underestimated (ASHA, 2023).

For young children with hearing loss to acquire spoken language, consistent use of appropriately fit hearing devices and exposure to quality linguistic input are crucial. However, parents may lack knowledge about hearing devices and language skills enhancement, necessitating additional support (Ambrose, Appenzeller, Margo, Jardin, and Jean, 2020).

During early childhood, a dynamic period of development encompasses cognitive, physical, and socio-emotional aspects. Cognitive abilities like language, memory, reasoning, visualization, and perceptual functioning are critical for successful interaction with the environment. Conversely, hearing loss can impede a child's communication skills and negatively impact cognitive development (Almmani et al., 2021).

Children with hearing disabilities require close monitoring and enhanced rehabilitation processes to address anxiety, depression, and overall quality of life. Given that parents of hearing-impaired children often have limited education, targeted educational efforts are essential to improve their approach to supporting children (Yigider, Yilmaz, Ulusoy, Kara, Kufeciler, and Kaya, 2020).

The responsibility of providing care to children with hearing loss can significantly impact caregivers, leading to physical, emotional, and economic stressors. Support systems, encompassing information, skills, respite, and financial aid, are crucial to enable informal caregivers to sustain their role (Nassrallah, Ken, JoAnne, Huidan, and Fitzpatrick, 2020).

Deafness transcends mere sound deprivation; it encompasses language deprivation. Hearing impairment, even of a mild nature, can profoundly affect language, social, emotional, and educational development in children. Early stages of social interaction between parents and the child are especially critical for later language development (Ambrose et al., 2020).

With more than half a billion people worldwide affected, hearing loss is the most common

sensory deficit. Its occurrence may result from issues in the ear, nerves, or the hearing part of the brain, leading individuals to use terms such as deaf, deafness, or hard of hearing. Addressing hearing problems, whether present from birth or emerging later in life, is crucial (Gavin, 2021).

Hearing loss, categorized as conductive or sensorineural, occurs when sound transmission from the outer ear to the brain is disrupted. If both pre and post the cochlea are affected, it is characterized as mixed hearing loss (Anastasiadou & Al Khalili, 2022).

Significance of the Study:

The significance of understanding parental awareness and knowledge of children with cochlear implants is underscored by findings indicating that 91% of parents receiving education had adequate information. In contrast, the control group, devoid of family counseling, exhibited lower awareness, with 57.3% possessing limited information and 30.9% having none at all (Sevinç and Şenkal, 2021)

Aim Of The Study

The aim of this study is to assess knowledge, practice and adjustment among family caregivers of children having hearing loss.

Research Hypothesis:

There is relationship between knowledge, practice and adjustment among family caregivers of children having hearing loss

Subjects And Methods

Research design:

A quasi-experimental to assessment the aim of the study.

Research Setting:

This study was conducted at the out-patient Speech clinic at Center of special needs care affiliated at the faculty of Post Graduate Childhood Studies at Ain Shams University.

Subjects:

A purposive sample was selected 40 from the studied family caregivers who meet inclusion criteria during their follow-up visits to the previously mentioned setting.

The criteria of the Subjects:

The criteria of the Subjects (Caregivers):

- Family caregivers who are responsible living with children having hearing loss.
- Free from other psychiatric disorders.

Sample size:

The sample size was 40 family caregivers of children having hearing loss. Equations for sample size Determination $n =$ Estimating the sample size was based on the study conducted by *Sevinç and Şenkal, (2021)*

Tools of Data Collection:

1. Demographic characteristics:

A. data characteristics of Family caregivers including age, sex, level of education, work hours during childcare and income.

B. data characteristics of the children with hearing loss, including age, gender and child's order.

C. Medical present history related to the health problem data such as the diagnosis of the child and the time of beginning of treatment.

2. Parent Knowledge and Awareness Questionnaire (PKAQ) was used to assess parents' knowledge and awareness of their child's hearing loss which include: the overall development of the child, information about hearing and hearing loss, the child's communication skills, and the hearing loss child's educational opportunities and getting information about the services.

Scoring System: The scoring system for each item (information) is a score (1) and No information (0) for each part.

3. Family Caregivers' Reported Practices Questionnaire was used to assess family caregivers' practices related to children with hearing loss. Which include: psychological and social interaction, dealing with behavior disorders, communication skills, attention, and concentration. The tool was faced content-validated by a jury group in psychiatric mental health nursing. The reliability of the practice checklists was tested through inter-rater reliability.

Scoring System: Family caregivers will be asked and record their responses on the family caregivers report practices questionnaire scoring system for each practice item will be done correctly is a score (2), sometimes a score (1), and will not be done (0) for each area of will be considered done correctly if the present score is 60% or more and will not be done if less than 60%.

4. An adjustment scale: it was developed by *Grant & Rivera, 2001 and modified by Ahmed, Guirguis, et al., 2018:* It includes 15 items related to the child when exposed to the disease.

Scoring System: This scale ranges from always (2), sometimes (1), and never (0). The scoring system of the adjustment scale is classified as follows: Mal adjustment (0-14) scores, Moderate adjustment (15-22) scores, and Adjustment (23-30) scores.

Preparatory phase:

It includes reviewing current, past, local, and international related literature and theoretical knowledge of various aspects of the study using books, the internet, articles, periodicals, and magazines to develop tools for data collection and program construction.

Validity: The tools were revised by five experts in Psychiatric Mental Health Nursing from the faculty of Nursing at Ain Shams University who revised the content of the tools for their comprehensiveness, accuracy, clarity, and relevance.

Reliability: was tested statistically by Cronbach Alpha. Reliability Cronbach's Alpha of Knowledge scale was 0.78, Cronbach's Alpha of Practice scale was 0.98 and Cronbach's Alpha of Adjustment scale was 0.83

A. Pilot study:

The pilot study was conducted on (10% = 4 cases) of the expected sample size to test the clarity, feasibility, and applicability of the study tools

Field work:

After taking necessary approvals, the researcher was determining a suitable time to collect the data and confirmed days, and times to conduct the strategy.

Statistical Analysis:

A descriptive design was used in this study; the data were collected and coded using the Computer Statistical Package for Social Science (SPSS), version 22, and was also used to do the statistical analysis of data.

Result

The study's results showed the following:

Table (2) shows that the mean age of the family caregivers was $27.3 + 1.219$, with 37.5% aged between 25 to 30 years, and 32.5% of them were above 35 years. Moreover, 87.5% of the studied families were female. Among the responsible caregivers, 45% were parents (both mother and father), while 42.5% were mothers. In terms of family income, 60% of them were not satisfied with their income. As for working

status, 25% of studied families did not work, and 42.5% of them had part-time jobs. Furthermore, 70.0% of them did not have another child with hearing loss.

In terms of education, 47% of family caregivers had a secondary school education, while 30% had a university education.

Table (3) The mean age of the children was $3.23 + .947$, with 37.5% aged 3 to 4 years. Also, 72.5% of the children were boys, and 40% were the first children among siblings. Additionally, 60% of the studied children went to nursery.

Table (3) Regarding hearing loss, 60% of children had mild to moderate hearing loss, and 35% of them started their treatment at 9 months or more. As for hearing aids, 37.5% of children did not use any hearing aids, only medication, and 32.5% of studied children were at the stage of preparation of speech.

Graphic (2) The study found that there was a statistically significant increase in the mean scores of total knowledge subscale and total

knowledge scale.

Graphic (3) The mean scores of total practice subscale and total scale scores of family caregivers of children with hearing loss were 57.50%, 53.75%, 55.34, and 54.03 (p-value < 0.001).

Graphic (4) Additionally, all total subscale scores of adjustments among the studied family caregivers were statistically significant

Table (5) However, there was no statistically significant relationship between knowledge, practices, and adjustment among the studied family caregivers and their demographic characteristics such as age, gender, who is responsible for childcare, education level, and work conditions.

Table (6) There was no statistically significant correlation between the studied variables (knowledge, practices, and adjustment) among the studied family caregivers (p-value > 0.05).

Table (1): Demographic data of family caregivers:

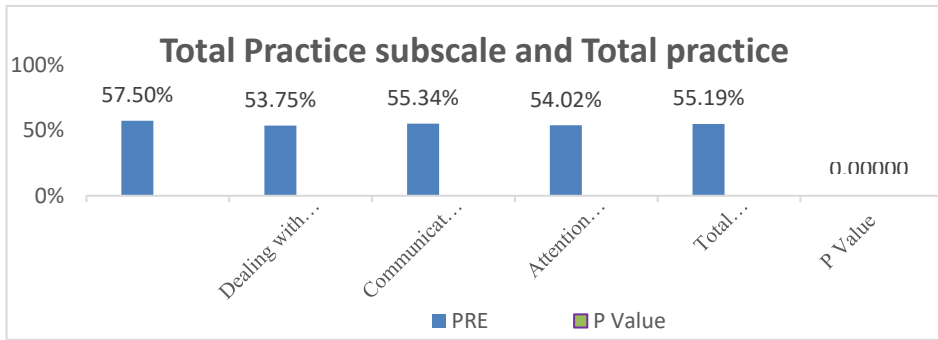
Items	N	%
Age of family caregiver		
> 25 years	6	15
25 ≥ 30 years	15	37.5
30 ≥ 35 years	6	15
≤ 35 years	13	32.5
Mean + SD = 27.3 ± 1.219		
The sex of family caregiver		
Male	5	12.5
Female	35	87.5
The family caregiver who is responsible for the child care		
Father	4	10
Mother	17	42.5
Parent(both mother& father)	18	45
Others	1	2.5
Working during care of the child		
Work full-time	7	17.5
Work part-time	17	42.5
Leave work or Don't work	10	25
Took unpaid leave to take care of a child	6	15
Monthly income		
Not enough	24	60
Enough	16	40
Is there another child in the family having hearing loss?		
No	28	70
Yes	12	30

Table (2): Demographic characteristics of children with hearing loss.

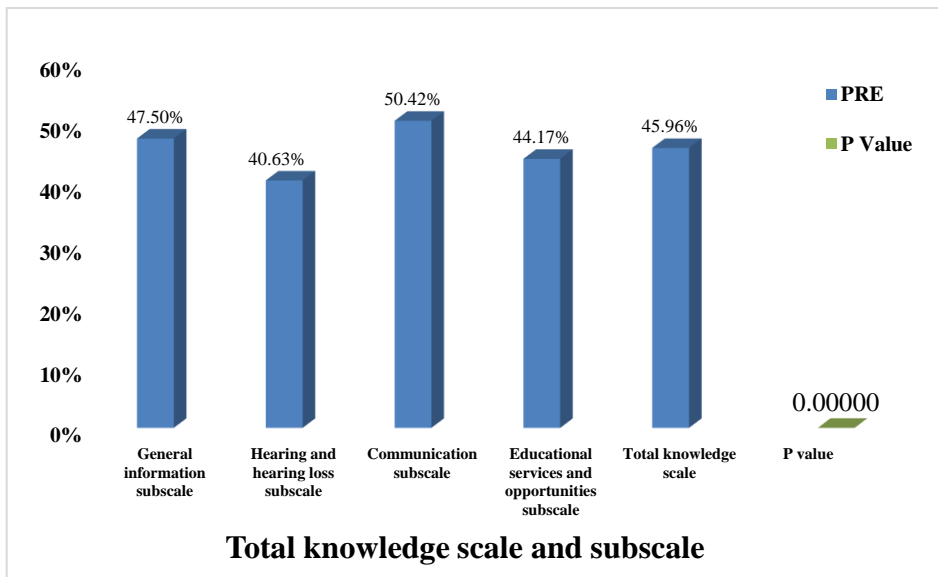
Items	N	%
Age of the child		
2 > 3 years	10	25.0
3 > 4 years	15	37.5
4 > 5 years	11	27.5
5 > 6 years	4	10.0
Mean + SD = 3.23+. 947		
Gender of child		
Boys	29	72.5
Girls	11	27.5
Child order between siblings		
First	16	40.0
Second	12	30.0
Third	10	25.0
Fourth	1	2.5
Fifth	1	2.5
Does the child go to the nursery?		
No	16	40.0
Yes	24	60.0

Table (3) Distribution of Health assessment data of children.

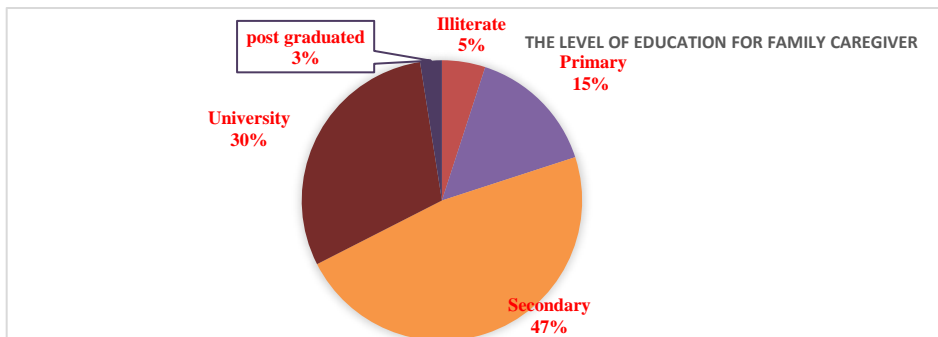
Items	N	%
Diagnosis of the child (severity of hearing loss)		
Mild	15	37.5
Moderate	9	22.5
Moderately severe	8	20.0
Severe	8	20.0
The time from the starting of treatment(month):		
0 ≥ 3months	7	17.5
3 months ≥ 6 months	10	25.0
6 months ≥ 9 months	9	22.5
9 months ≥ one year	14	35.0
Child's use of hearing devices		
Hearing aid in one ear	8	20.0
Hearing aids in both ears	9	22.5
Cochlear implants	8	20.0
Not use any hearing aids only medication	15	37.5
At any stage of treating hearing loss for the child		
Diagnostic stage	9	22.5
treatment stage	10	25.0
stage of using the auditory equation	8	20.0
Stage of preparation of the speech	13	32.5



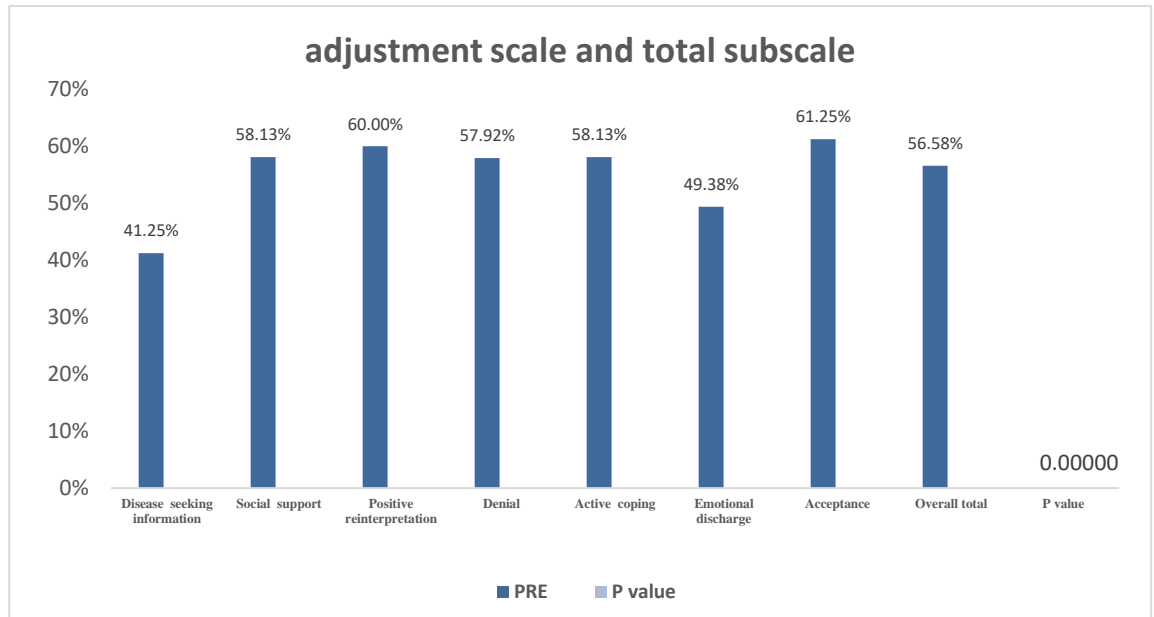
Graphic 1: level of education for studied family caregivers of children having hearing loss.



Graphic (2): Total knowledge and total subscale among the studied family caregivers.



Graphic (3): Total Practice Subscale and Total scale among studied family caregivers.



Graphic (4): Total adjustment scale and subscale among studied families’

Table (6): Correlation between (Knowledge, adjustment & practices) among studied family caregivers.

Knowledge		Practices		Variables
Pearson correlation coefficient	P Value	Pearson correlation coefficient	P Value	
0.19	0.24316 P > 0.05 NS	0.15	0.36715 P > 0.05 NS	adjustment
0.24	0.14027 P > 0.05 NS			practices

Discussion

Hearing impairment has a significant impact on both the child and the mother. In children, the problem is compounded since normal hearing provides the primary source for the acquisition of language, speech, and cognitive skills. The HI can cause delays in the development of communication skills, learning problems that result in reduced academic achievement and communication difficulties which often lead to social isolation. Early interventions in the form of mothers' psychological support will help them overcome the effects of their children's disability. (*American Speech-Language-Hearing Association, 2020*).

So, the present study had been designed to evaluate the effect of psycho-educational program for enhancing knowledge, practice,

and adjustment among family caregivers of children having hearing loss.

Concerning demographic data of studied family caregivers, the present study results revealed that, age of family caregivers showed that more than one third (37.5%) of the studied family caregivers was aged ranged from twenty-five to more than thirty years, followed by about one third (32.5%) aged above thirty-five years with the mean 27.3 + 1.219. From the researchers' point of view This may be due to age of mothers was important factor in providing knowledge and understanding new experience with care. This finding was agreed with *Abd EL- Ghany et al. (2023)* who evaluated in a study at Benha University about "Effect of an educational program on mothers' knowledge, practice, empowerment and

satisfaction regarding caring of their children post cochlear implant” and showed that, more than one third ranged between 25-30 with the mean age was 25.070 ± 5.0936 . Also, these findings were consistent with the findings of the study done by *Zaidman-Zait et al., (2017)* entitled "Mothers' and fathers' involvement in intervention programs for deaf and hard of hearing children. Disability and Rehabilitation", who reported that, caregivers' age is between 25 to 35 years old, with Mean \pm SD= 30.77 ± 4.99 .

As regard gender of family caregivers, the findings of the current study revealed that, the majority (87.5%) of the study sample were female.

On country, this result was inconsistent with the result of the study of *Mohammed et al. (2020)* who conducted a study at Minia city in Egypt, about “Assessment of Knowledge and Attitudes of Caregivers Regarding Hearing Impairment among Children at Minia City” and reported that, majority (96.0%) of the study sample were female.

Regarding the responsible caregivers, the current study revealed that, less than half (45%) of the responsible caregivers were parent (both mother and father). This finding was disagreed with *El Mezayen et al. (2023)* who conducted a study in Tanta, Egypt, about “Attitudes and Practices of Parents toward their Children Suffering from Hearing Impairment, using Hearing Aids and Challenges Facing them” and reported that, less than half (45%) of (45%) of the responsible caregivers were father.

Regarding another child in the family having hearing loss the current study showed that more than two thirds (70.0%) hadn't another child in the family with hearing loss. These finding was in agreement with *Abd EL- Ghany et al. (2023)* who reported that, the majority of them hadn't another child in the family with hearing loss. Also, these findings were agreement with studied by *Continisio et al. (2023)* who conducted study in Torino, about “Parenting stress in mothers of children with Permanent Hearing Impairment” and revealed that less than half (49%) mothers had not other brothers and sisters with hearing loss.

As regard **qualification**, slightly less than half of family caregiver have secondary school education represent 47% while one third of them represent 30% have university education. These finding was in agreement with the study

conducted by *Aljabri et al. (2019)* in King Khalid University Hospital's (KKUH) pediatric clinics about “Parental knowledge and attitudes towards childhood hearing loss and hearing services in King Khalid University Hospital's (KKUH) pediatric clinics” and reported that, more than half (55.7%), of the studied sample had a college education level while most of the rest had a secondary education level.

Concerning characteristics of child with hearing loss. In relation to, age of children, the current study revealed that the mean of the child age was Mean + SD = $3.23 + .947$ and more than one third (37.5%) of children aged $3 \geq 4$ years. This finding was agreed with *Abd EL- Ghany et al. (2023)* who indicated that, more than one third (40%) of children aged $3 \geq 4$ years.

Regarding to gender of children having hearing loss, the current study revealed that less than three quarters (72.5 %) of children were boys. These results were in agreement with *Soleimani et al. (2020)* who conducted a study in Iran, about “Comparing the prevalence of attention deficit hyperactivity disorder in hearing-impaired children with normal-hearing peers that (64.6%) were boys and 46 (35.4%) were girls.

Concerning child order between siblings, the current study revealed that, about, two fifths (40%) of Children were first children order among siblings. This finding was agreed with *Hamad et al. (2022)* who reported that more than two fifths (48%) of Children were first children order among siblings. As regard to going to nursery, the current study revealed that, about three fifths (60%) of the studied went to the nursery. This finding was also disagreed with *Hamad et al. (2022)* who revealed that less than three fifth (54%) of the studied did not go to the nursery.

Concerning Health assessment of children having hearing loss, the present study showed that the severity of hearing loss, the current study revealed that, more than one third (37.5%) of children were mild for severity of hearing loss, while less than one quarter (20.5%) of children were moderate for severity of hearing loss. These finding was in the same line with *Hamad et al. (2022)* who revealed that, less than one third (28.7%) of children were mild for severity of hearing loss, while more than one fifth (20.7%) of children were moderate for severity of hearing loss

Conversely, these finding was disagreed with *El Mezayen et al. (2023)* who revealed that more Than one third (33.7%) of children were severe hearing impairment and 7.1% had mild hearing impairment.

Regarding to the time of beginning started their treatment, the current study revealed that, more than one third (35%) of children were started their treatment from 9 months \geq one year. These results were agreement with *Continisio et al. (2023)* who revealed that about one third (32%) of children were the time of diagnosis 7–12 months.

In relation to children using hearing aids and stage of treating hearing loss, the current study revealed that, less than half (42.5%) of children using hearing aids, and about one third (32.5%) of studied children at the stage of preparation of the speech, respectively. These results are agreement with *Ambrose et al. (2020)* who conducted study, about “Beliefs and self-efficacy of parents of young children with hearing loss” and stated that more than two thirds (66.76%) of children using hearing aids and Start speech preparation.

The study found that family caregivers of children having hearing loss had fair scores in terms of knowledge, practice, and adjustment. This is in agreement with the findings of *Ahmed et al. (2019)*, but contradictory to the findings of *Salah et al. (2022)*.

There was no statistically significant correlation between knowledge, practice, and adjustment among family caregivers of children having hearing loss and sociodemographic characteristics such as age, gender, responsible for child care, education level, and work conditions. This result is consistent with the study by *Kadi& Eldeniz (2018)* and *Olayinka B.T. (2023)*.

The study found no correlation between knowledge and practice, knowledge and adjustment, practice, and adjustment among family caregivers of children having hearing loss. This result is contradictory to a study by *Ahmed et al. (2018)*.

Conclusion

The results of this study concluded that, there is no correlation between knowledge, practice, and adjustment among family caregivers of children with hearing loss.

Recommendations

This study recommends that families of children with hearing loss, that families have access to educational resources, such as booklets and training programs, to better support their children. Service providers can also establish training programs for family caregivers to improve their understanding and skills. Additionally, future research should focus on replicating this study on a larger sample size and developing tools to measure changes in family caregivers' knowledge, practice, and adjustment.

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