

Effect of Social-Platform Instructional Guidelines on Pediatric Mothers' Knowledge and Anxiety regarding Alport Syndrome

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Abstract

Background: Alport syndrome is a hereditary kidney disease that gradually deteriorates kidney function and frequently leads to renal failure. A multitude of detrimental effects, such as mothers becoming more concerned and anxious about their children's physical and mental health, can result from certain forms of Alport syndrome, which also create various symptoms and indicators in children, such as hearing loss and eye abnormalities. **Aim:** To evaluate the effect of social-platform instructional guidelines on pediatric mothers' knowledge, and anxiety regarding Alport Syndrome. **Design:** to fulfill this study a quasi-experimental research design was used. **Setting:** This study was conducted in Sohag City, Egypt. **Sample:** A total purposive sample of 300 mothers from 10 and 30 July 2023 was obtained using an online questionnaire via Google Forms. **Tools:** Three tools were utilized: Tool I: Nurses' knowledge regarding Alport Syndrome, Tool II: Future anxiety scale, and Tool III: Nurses' satisfaction with social-platform instructional guidelines implementation. **Results:** The study showed that nurses' understanding of Alport Syndrome was higher after the social platform instructional guidelines were implemented than before. After the social-platform instructional instructions were implemented, the moms in the study experienced a reduction in their anxiety levels. Mothers' overall awareness of Alport Syndrome and their anxiety levels were positively correlated, with a significance level of 0.01 after implementation. **Conclusion:** The study concluded that mothers' knowledge and anxiety levels are improved when social media platforms are used to implement instructional guidelines about Alport Syndrome. **Recommendations:** A well-thought-out health education program that enhances mothers' understanding of Alport Syndrome and reinforces potential interventions is crucial for supporting and assisting with psychological well-being.

Keywords: Anxiety, Alport Syndrome, Knowledge, Mothers, Social-platform instructional guidelines.

Introduction

Alport syndrome is a kidney disease that causes blood and excess protein in the urine and, over time, frequently results in a decline in kidney function. Dialysis or a kidney transplant may eventually be necessary due to this decline in kidney function. A certain amount of hearing loss may be the outcome of Alport syndrome's effects on the eyes and ears. A genetic mutation that can be inherited from one's parents causes Alport syndrome. COL4A5, the mutated gene responsible for Alport syndrome, aids in the production of the proteins that make up the kidneys' filters. The eyes and ears can also be

affected by Alport syndrome because the same protein, collagen, is required to form these tissues (Savige, 2020).

The X chromosome is home to the gene mutations that cause Alport syndrome. Since females have two copies and males only have one, females are more likely to have at least one healthy X chromosome. Accordingly, Alport syndrome primarily affects men and affects them more severely than it does women. It is uncommon to observe severe cases of Alport syndrome in females, but they may "carry" the mutation and experience minor symptoms (Zhang & Ding, 2018).

Three distinct genetic types of Alport syndrome are distinguished by the way the X

chromosome is impacted; the most prevalent is X-linked Alport syndrome (XLAS). Autosomal recessive Alport syndrome (ARAS), the second most prevalent kind, usually affects males more severely than females. This variety is the least prevalent, with Autosomal dominant Alport syndrome (ADAS) having a similar severity in affected boys and females. This kind of sickness is severe and equally affects men and women (**Savage et al., 2019**).

Reduced renal function typically does not begin until well into adulthood, and the signs and symptoms of ADAS typically appear more slowly. According to **Kashtan (2022)**, people with Alport syndrome may also experience gradual hearing loss of different intensities. Vision impairment is not typically the outcome of eye issues. Urine-containing blood, either visible or identified by dipstick testing, is frequently the first indication of Alport syndrome. A family history of Alport syndrome is common as well, particularly in male relatives, because the mutations that cause the condition are typically inherited. The kidneys' inability to filter poisons from the blood as effectively is a sign of decreased renal function. The following are some indicators of impaired kidney function: blood in the urine, Fluid accumulation causing edema in the abdomen, High blood pressure, Weakness and fatigue, Malaise (a general feeling of discomfort or illness), Fever, Weight loss (**Cosgrove, 2022**).

A kidney biopsy involves taking a little sample of kidney tissue and looking at it under a microscope. To diagnose or confirm Alport syndrome, genetic testing may also be useful. A blood sample or a simple saliva swab can be used to collect a sample for a genetic test. When acanthocytes, red blood cell casts, abnormal renal indices, or abnormal UA are present, a renal biopsy is recommended. Referrals to ophthalmology for an eye examination and otorhinolaryngology for an assessment of high-frequency hearing loss should be made for any patient suspected of having Alport syndrome. Because of the damaged collagen, the lens is unable to keep its natural shape, which causes the anterior lenticonus to develop into the anterior chamber (**Raimundo et al., 2019**).

Alport syndrome has an impact on

several organ systems. The following consequences may result from it: mental retardation, thoracic and abdominal aortic aneurysms, leiomyomatosis (smooth muscle overgrowth in the respiratory and gastrointestinal system), hearing loss, visual impairments, and end-stage renal disease (ESRD) (**Gross et al., 2020**).

Because Alport syndrome is caused by irreversible defects in the protein building blocks of the kidney filters, there is no known cure. To limit urine protein losses, normalize high blood pressure when it occurs, and treat any problems brought on by impaired kidney function, the treatment is supportive. These problems, in addition to high blood pressure, can include growth failure, bone damage, anemia (low red blood cell count), and elevated acidity in the body. Kidney transplantation and dialysis are eventually necessary if the decline in kidney function worsens over time.

. The preferred treatment for children whose own kidneys are failing due to Alport syndrome is kidney transplantation, which gives your child a healthy kidney with proper building blocks. We usually treat any associated hearing loss with hearing aids. To accomplish this, we work with the Otolaryngology Department, which specializes in treating hearing loss in children (**Cosgrove, 2022**).

Because Alport syndrome affects several organ systems, it is treated using a multidisciplinary approach. Treatment and management of Alport syndrome entail a geneticist, otorhinolaryngologist, nephrologist, internist, intensivist, and ophthalmologist. It may also be required to consult with a transplant surgeon, a surgeon, a dialysis specialist, and an audiologist (**Nicklason et al., 2020**).

Combining a mother's melancholy with an overly protective attitude toward a son who has Alport syndrome was one of the patterns that kept happening. This made it evident that families with any kind of Alport syndrome should be encouraged to talk freely about the past experiences of family members, as well as

their expectations, hopes, and feelings of guilt or fear. This approach requires a sympathetic mindset and the doctor's role. It appears that mothers whose children have Alport syndrome and who show little to no symptoms of the illness require extra psychological care (**Pajari & Sinkkonen, 2020**).

The mother plays a crucial role as the children's primary caretaker. They have been associated with anxiety and despair. Chronic illness may raise a child's risk of contracting the illness and have several negative effects, including making mothers more fearful and anxious about their children's health (**Brooks et al., 2020**). According to **Davenport et al. (2020)**, mothers of children may also experience psychological distress from other sources, such as their children's safety and well-being.

Future anxiety (F.A.) is characterized as a condition of unpredictability, fear, and concern about potentially dangerous changes in one's future. Because they want their children to grow up to be the happiest, healthiest individuals possible, mothers naturally consider their children's future. A tendency to ponder about the future could result in F.A. Mothers feeling more secure and optimistic about the future than those at any other stage of life. F.A. sufferers struggle with humor, experience more unpleasant psychological symptoms, and doubt their ability to cope with difficult situations in the future. Therefore, mothers should be aware of the issue of F.A. (**Kaya & Avci, 2019**).

Accordingly, anxiety and mental distress may be exacerbated by ignorance and misunderstandings about Alport syndrome. Mothers may have different information needs, therefore evaluating their knowledge is especially important for identifying gaps and strengthening current preventive measures (**Podder et al., 2019**). For mothers to manage their anxiety and adapt to this new circumstance, they need to be given the right information, asked about their fears taught how to recognize and confront their negative thoughts, and given a sense of control over their children's risk of illness (**National Association of School Psychologists 2016**).

Electronic education is one of the contemporary methods of instruction. It combines many tools and technology to provide instructional content. These tools and technologies include, but are not restricted to, computer simulation modeling, multimedia software, compact discs, complex networks like the internet and extranet, and electronic media. According to **Lawn et al. (2017)**, social-platform education is an extension of electronic education that promotes creativity and increases educational effectiveness by combining many media to enable interaction between students and software.

The primary objective of social-platform education is to assist students in reaching greater knowledge and proficiency levels. Social platform education has the benefit of being easily applicable to those with low literacy levels. Research on the use of social media platforms to educate patients with chronic illnesses (**Abbasi et al., 2018**), prostate cancer patients getting ready for radiation therapy (**Dawdy et al., 2018**), and patients undergoing lumbar disc surgery (**Zarei et al., 2018**)

Nurses played a crucial part in giving Alport syndrome patients pre-ESRD education so they could talk about the different alternatives and problems related to renal replacement therapy (e.g., dialysis, transplantation). Get nutritional advice for patients who are getting close to end-stage renal disease. Patients with Alport syndrome should not receive nephrotoxins, such as over-the-counter nonsteroidal analgesics. In patients who don't have any symptoms, emphasize the value of annual physicals and lab tests. Patients should be advised to have visual and audiometric testing done every two years. Parents who have Alport syndrome or who may be carriers of the condition should be encouraged to seek genetic counseling. Individuals who were previously thought to be healthy become aware of their genetic predisposition to either develop an illness in the future or pass it on to their descendants when they learn about the existence of genetic diseases (**Cosgrove, 2022**).

Nurses should provide patients with

informational pamphlets about the signs and symptoms of renal failure and its systemic effects. Parents of afflicted children should be aware of the disease's symptoms and indicators that call for hospitalization. To undergo screening by local recommendations, family members of people with Alport syndrome should speak with their primary care physicians. Before marriage and childbearing, patients with Alport syndrome should receive genetic counseling. Patients and their family can better manage their situation with the help of a variety of support organizations (**National Association of School Psychologists 2020**).

Significance of the study:

Mothers have a special set of difficulties in juggling their children's requirements, particularly their health. Youngsters were at serious risk of getting a disease that would affect them in multiple ways, which made their mothers more anxious. Mothers worry about their children's health a lot because they are the ones who are caring for them.

Alport syndrome is a hereditary condition that affects the kidneys' basement membrane and can also affect other organs like the eyes and inner ear's cochlea. It is typified by mutations that result in anomalies in the collagen found in the basement membrane, which is essential to the kidneys' filtration function. Chronic renal disease is frequently the outcome of these anomalies, which cause increasing kidney damage. In certain instances of Alport syndrome, sensorineural hearing loss may result from the aberrant collagen's impact on the inner ear's cochlea. Vision issues can also arise from anterior lenticonus, which is an alteration in the ocular lens. Individual differences exist in the manifestation and severity of Alport syndrome (Cosgrove, 2022).

The technological revolution has created new opportunities to increase access to mental health therapies that work. Technology-delivered therapy is useful for health difficulties, according to new research (**Podina et al., 2019**). Because online therapy offers the benefits of flexibility in terms of time, place, and cost, it may be readily accepted (**Song et al., 2019**). Additionally, individuals with

chronic illnesses can integrate pathology management with their regular social lives through technology-enabled schooling at home (**Di Tella, et al. 2019**).

Operational definitions:

Social media platforms are web-based communication tools that enable people to interact with each other by sharing and consuming information. Available social media in this article are Mobile phones, Messenger, and WhatsApp.

Alport syndrome is a hereditary genetic disorder that is characterized by progressive kidney disease, sensorineural hearing loss, and ocular abnormalities. Alport syndrome can also occur due to de novo mutations, where a new genetic mutation arises spontaneously in an affected individual without a family history of the condition. Genetic testing is necessary to determine the specific type of Alport syndrome in each affected individual and their family members.

Aim of the study:

To evaluate the effect of social-platform instructional guidelines on pediatric mothers' knowledge and anxiety regarding Alport Syndrome through:

- Assessing the mothers' knowledge about Alport Syndrome pre and post-social-platform instructional guidelines.
- Assessing the mothers' anxiety regarding Alport Syndrome pre and post-social-platform instructional guidelines.

Research hypothesis:

The introduction of social-platform teaching guidelines will improve mothers' knowledge of Alport Syndrome and lower their anxiety levels.

Subjects and Methods

Research design:

This study was conducted using a quasi-experimental research approach, and a pre-and post-test was utilized to assess participants' knowledge of how to apply the material covered in a training session or when a new

topic was introduced.

Research Setting:

This study was carried out in Sohag City, Egypt, utilizing a Google Form to administer an online questionnaire. The link to the form is <https://docs.google.com/forms/dle/1FALPQKh d>.

Subjects:

Using an online questionnaire via Google Forms, a purposive sample of 300 mothers was selected between July 10 and 30, 2023, from social media groups on Facebook and WhatsApp. These mothers met the following inclusion criteria: they were educated mothers between the ages of 20 and 40, they already used social media, they consented to participate in the study, they had no history of mental illness, and they all completed the pre- and post-test. These mothers filled out a Google Form online between July 10 and July 30, 2023, for roughly 20 days before the link was shut off.

Tool of the study:-

Three tools were used in the current study:

Tool I: Mothers' knowledge regarding Alport syndrome, It was developed by the researchers after reviewing the related literature (Cosgrove, 2022; National Association of School Psychologists 2020). It was used to assess the following two parts:

Part 1: Demographic data of mothers: It included demographic characteristics of the studied mothers which consisted of 4 items related to age, educational level, occupation, and residence.

Part 2: Mothers' knowledge regarding Alport syndrome:

It was used to assess mothers' knowledge about Alport syndrome (pre and post). It assesses the main concepts in Alport syndrome, which included 12 open-ended questions about definition of Alport syndrome (1 question), causes of Alport syndrome (1 question), incidence of Alport syndrome (1 question), types (1 question), diagnosis (1 question), clinical manifestation (1 question), **Urine Tests** (1 question), preventing measures (1 question), medical treatment (2 questions), complications (1 question) and nursing care (1

question). This questionnaire was distributed in the same form two times (pre and post-guidelines implementation) for the same group of mothers.

The scoring system

The percentages of mothers who knew and didn't know the answers were computed. Each fully accurate response received two marks, while incompletely correct responses received one mark each, and incorrect or unknown responses received zero marks. The mean score for each knowledge area was calculated by adding up all of the item scores and dividing the total number of answers by the number of items. Following that, a percentage score was created from these scores. If a mother's knowledge score was 60% or more, it was deemed satisfactory; if it was less than 60%, it was deemed unsatisfactory.

Tool II: Future anxiety scale

As shown in the accompanying table, it was created by Shekhair (2005) and adjusted by the researchers according to our culture. It has five domains (20 things): future anxiety and fear (4 items), future anxiety and despair (5 items), future anxiety and worry thinking (5 items), health and death anxiety (3 items), and future anxiety related to the problem (3 items).

Domain	Items number of a standardized tool	Items number of modified tool
Fear and worries about future	1, 2, 5, 15, 27	1, 5, 15, 27
Despair of the future	4, 7, 8, 9, 12, 16	4, 8, 9, 12, 16
Worry thinking about the future	3, 6, 11, 13, 14, 23, 28	11, 13, 14, 23, 28
Health and death anxiety	10, 18, 19, 25, 26	19, 25, 26
Future anxiety related to the problem	17, 20, 21, 22, 24	17, 21, 24
Total future anxiety	1 – 28	1 – 20

The Scoring system:

Five Likert scales were employed: zero for always, two for moderate, three for maybe, four for never, and one for a lot. Zero for never, one for maybe, two for moderate, three for a lot, and four for always were the reversal scores for the statement. Total scores were classified as low (0–15), mild (16–31), moderate (32–48), high (49–64), and extremely high (65–80).

Tool III: Nurses' satisfaction with social-

platform instructional guidelines implementation: It contained three assertions that were unambiguous about the content of the social-platform instructional guidelines: the implementation of these guidelines enhances mothers' knowledge and lessens their anxiety.

The procedure of data collection:

Preparatory phase:

To establish the social-platform instructional guidelines for implementation and to develop the tools for data collecting, the researchers looked at the existing and previous literature, including published textbooks, papers, periodicals, and online searches. The dean of the nursing faculty sent a formal letter to the management of Sohag University Hospital before the study's commencement, asking for their cooperation and consent to collect data from the chosen location.

Validity of the tools:

Five professionals who have over 10 years of experience in the fields—three pediatric nursing professors and two psychiatry health nursing professors—evaluated the face and content validity of the instruments for clarity, comprehensiveness, appropriateness, and relevance to determine their face and content validity. The instrument had an 89% content validity index (CVI).

Reliability of the tools:

The reliability was evaluated using Cronbach's alpha reliability test, and the results showed that the first tool had reasonably homogenous items, as indicated by high reliability ($\alpha = 923\%$), the second tool was reliable ($\alpha = 87\%$), and the third tool was reliable ($\alpha = 819$). By comparing variables using the Pearson correlation coefficient test, the reliability of the instruments was determined. The variables' Pearson correlation coefficients varied from $P < 0.5$ to $P < 0.001$, indicating a highly significant positive connection between the participants' variables.

A pilot study

A pilot study including 30% of the mothers was carried out following the tool's creation. It was taken out of the entire sample. It was

carried out to identify any ambiguities in the instruments, guarantee item transparency, and find out how much time was spent gathering data. Based on the pilot study's findings, the research procedure required for revisions was clarified and its viability was tested to create the tools' final version.

Ethical considerations:

The study was submitted for the approval of the ethical committee of the research. Official permission was obtained through an issued letter from the Dean of the Faculty of Nursing, Sohag University to conduct this study. The purpose of the study was explained to the mothers in the first part before starting the questionnaire the researcher informed the participants that, the study was voluntary, they were allowed to refuse to participate and they had the right to withdraw from the study at any time, without giving any reason. Moreover, they were assured that their information would be confidential and used for research purposes only.

Administrative design:

To conduct this study and secure authorization for data collecting, the directors of the department that was initially chosen received a letter from the Faculty of Nursing granting administrative authority.

There were three stages to the study's implementation: assessment, implementation, and evaluation.

I-Assessment phase:

The real fieldwork was conducted from July 10th, 2023, to July 30th, 2023. To create the research, the researchers used an online Google form spreadsheet. To gather information, they sent the participating mothers a link to online surveys. Groups on Facebook and WhatsApp shared this link. The study's background, goals, and anticipated results were explained to the moms on the first page of the questionnaire.

To determine the mothers' knowledge and anxiety about Alport Syndrome (pre-implementation of instructional instructions),

the following link was emailed to all of the mothers in the study: <https://docs.google.com/forms/dle/1FALPQKh d>.

We used the future anxiety measure and the online questionnaire twice. For the first time, they used a pretest to gauge the moms' anxiety levels and understanding of Alport Syndrome. These tools were then utilized again as a follow-up two weeks later to evaluate the effect of social-platform instructional guidelines on pediatric mothers' knowledge and anxiety regarding Alport Syndrome.

Mothers completed the future anxiety scale and the online questionnaire in an average of about twenty-five minutes. The goal of the study, the components of the instruments, and instructions for completing the online questionnaire and scale were explained to each mother who participated.

Once the researchers had outlined the goal of the study, they sent the instructional guidelines to the participating mothers in Facebook groups and WhatsApp app groups and gave them instructions on how to use them.

II-Implementation Phase:

After the link was closed, data was gathered for roughly 20 days, from July 10 to July 30, 2023. To begin, the researchers gave the

The content of the instructional guidelines is presented in the following table.

Session NO	Subject content	Teaching methods
1	An introduction session that focused on building rapport between the researchers and the mothers who were being investigated and outlining the program's goal	Discussion
2	Education about Alport Syndrome includes questions about definition, causes, manifestation, incidence, and complications.	Powerpoint presentation Discussion
3	Education about types, diagnosis, Urine Tests , prevention measures, medical treatment, and nursing care of Alport Syndrome	Teaching videos
4	Teaching parents about future anxiety (including its description and the signs and symptoms of Alport Syndrome-related future anxiety that their kids might experience). A healthy daily routine, addressing negative thoughts, communicating effectively with others, and asking for and receiving support from friends, family, and others to increase one's sense of security are all strategies for managing anxiety.	Powerpoint presentation Discussion

mothers an introduction and explained the purpose and nature of the study. An online-prepared Google Form was given to participants to complete and submit. Mothers were notified through Facebook and WhatsApp groups about the link to the Google form. To get baseline data, each mother was given an online questionnaire to complete before the online videos and presentation. The purpose of the study, its anticipated results, the contents of the instruments, and how to complete the first page of the online questionnaire were explained to the mothers. In this phase, the researchers met the study subjects online through Zoom meetings through voice calls, videos, and chat.

Sessions, which included six theoretical and practical sessions, were conducted in Arabic to guarantee that all study topics were comprehended. Each theoretical and practical session lasted 45 to 55 minutes, and they were held twice a week. A Google Form was used to distribute the booklet to mothers who took part in the pre-test through Facebook and WhatsApp groups. To help mothers better understand menopause, the researchers produced PowerPoint presentations, movies, and posters. The researchers also produced audio and video content for the internet that explained the booklet's contents to educate moms and lessen their worry.

Session NO	Subject content	Teaching methods
5	It included strategies for managing the mothers' anxiety related to Alport Syndrome, such as educating them about meditation (definition, steps, and practice) and the value of deep breathing and muscle relaxation exercises.	Powerpoint presentation Teaching videos
6	Summary of the program and the studied mothers were asked to answer the questionnaire in the online link post instructional guidelines.	Discussion

Evaluating the social platform instructional guidelines:

Three pediatric nursing professors, two psychiatry health nursing professors, and five expert professors assessed the social platform instructions. The social platform teaching guidelines and contents for Alport Syndrome were reviewed by the subject matter experts to guarantee clarity and appropriateness.

The general objectives of the social platform instructional guidelines were to improve mothers' knowledge and anxiety regarding Alport Syndrome.

Specific objectives: At the end of the social platform instructional guidelines the studied mothers were able to:

- 1- Define of Alport Syndrome.
- 2- Incidence of Alport Syndrome
- 3- List symptoms of Alport Syndrome.
- 4- Enumerate the causes of Alport Syndrome.
- 5- List types of Alport Syndrome.
- 6- List complications of Alport Syndrome.
- 7- Identify urine tests.
- 8- Define future anxiety.
- 9- Enumerate symptoms of future anxiety resulting from Alport Syndrome
- 10- Demonstrate and discuss techniques to cope with future anxiety regarding Alport Syndrome.
- 11- Discuss prevention measures, medical treatment, and nursing care for Alport Syndrome.

III. Evaluation phase:

Two weeks after sending the booklet, videos, PowerPoint presentation, and posters (post-test), the participants were given another

chance to complete the questionnaire via the Google Form to re-evaluate the effect of social-platform instructional guidelines on pediatric mothers' knowledge, and anxiety regarding Alport Syndrome using the same tools used in the pre-test.

Statistical analysis:

For data entry and statistical analysis, SPSS for Windows, version 20, was used. Descriptive statistics were used to present the data, including mean and standard deviations for quantitative variables and frequencies and percentages for qualitative variables. The most popular and suitable tests for analyzing SPSS data were the Chi-Square test for categorical data comparison and the t-test for continuous data comparison between two groups. The significance of the results was evaluated using the 0.05 level as the cut-off value for statistical significance.

Results:

Table 1 displays the demographic details of the mothers under study. The mean age of the moms in the study was 27.3 ± 2.1 years, and 45% of them were between the ages of 20 and 30. In terms of education, a majority of them (75%) lived in cities, 65% were housewives, and 35% had graduated with a bachelor's degree.

70% of the mothers in the study stated that doctors were the primary source of their knowledge on Alport Syndrome, as seen in Figure 1.

Table (2) shows a very statistically significant difference in the total knowledge scores between the moms in the study who were taught about Alport Syndrome before and after social platform instructional guidelines (P-

value: 0.001).

According to Figure (2), during the pre and post-social platform instructional guidelines, the majority of mothers (90%) had inadequate understanding regarding Alport Syndrome; however, 94% of them had adequate knowledge after the social platform instructional guidelines.

Table (3) shows that a highly statistically significant difference was detected (P-0.001), the mean score of dread and future anxieties among the moms in the study decreased after following the social platform instructional guidelines as opposed to before. Before and after social platform instructional instructions, the mean score for health and death anxiety was 6.6 ± 3.3 and 3.9 ± 2.4 , respectively. These variations were very statistically significant (P-0.0001). When compared to the pre-social platform instructional guidelines, the mean score for total future anxiety decreased after the social platform instructional guidelines, with a highly statistically significant difference found (P-0.0001).

Following the social platform instructional guidelines, the moms in the study showed a decrease in their overall degree of future fear

(Figure 3). It was shown that just 3% of the moms in the study experienced serious future worry after following the social platform instructional guidelines, compared to 30% who did so before.

Table 4: shows that there was a moderately negative association ($r=-0.563$, P value<0.0001) between the mothers' educational level and their knowledge. Additionally, there was a moderately negative connection ($r=-0.508$, P value<0.0001) between mothers' residence and their level of future anxiety.

Table 5 shows a moderately negative link between the mothers' knowledge of the study and their worry about the future after following the social-platform instructional guidelines.

Illustration (4): demonstrates that all of the mothers who were the subject of the study (100%) expressed satisfaction with the social platform teaching guidelines and that the advice was clear. Regarding its impact on their level of knowledge and anxiety, 97% of them reported that the social platform's instructional guidelines increased their knowledge and decreased their worry.

Table (1): The Studied Mothers according to their Demographic data (n=300)

Demographic data	NO.	%
-Age(years):		
20 < 30	135	45.0
30 - 35	105	35.0
35 ≥40	60	20.0
Mean and SD (27.3±2.1)		
-Educational level:		
Postgraduate	21	7.00
Bachelor's degree	105	35.00
Technical Institute	84	28.00
Secondary school diploma	90	30.00
occupation		
Housewives	195	65.00
Working	105	35.00
- Residence		
Urban	225	75.00
Rural	75	25.00

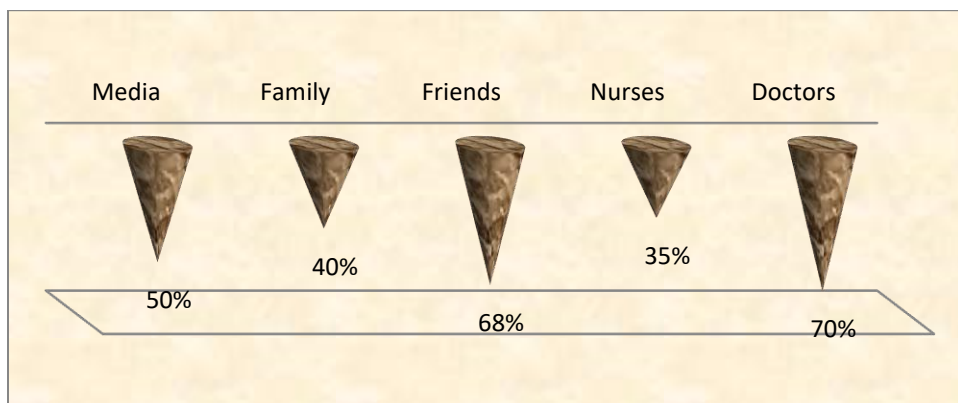


Figure (1): Source of Knowledge regarding Alport Syndrome among the Studied Mothers

Table (2): Comparison between Mean Scores of Knowledge among the Studied Mothers about Alport Syndrome Pre and Post Social Platform instructional guidelines (n=300)

Items	Pre-social platform instructional guidelines	Post social platform instructional guidelines	t-test	P-value
General knowledge about Alport Syndrome	2.6 ± 0.8	4.8 ± 0.5	19.183	0.0001**
Signs & symptoms, causes, types, incidence, and complication	3.7 ± 2.3	9.2 ± 1.0	17.532	0.0001**
Preventing measures, medical treatment and nursing care of Alport Syndrome	3.0 ± 1.9	6.8 ± 0.4	16.627	0.0001**
Total knowledge scores	8.5 ± 3.5	19.8 ± 1.2	24.139	0.0001**

**Highly statistically significant differences

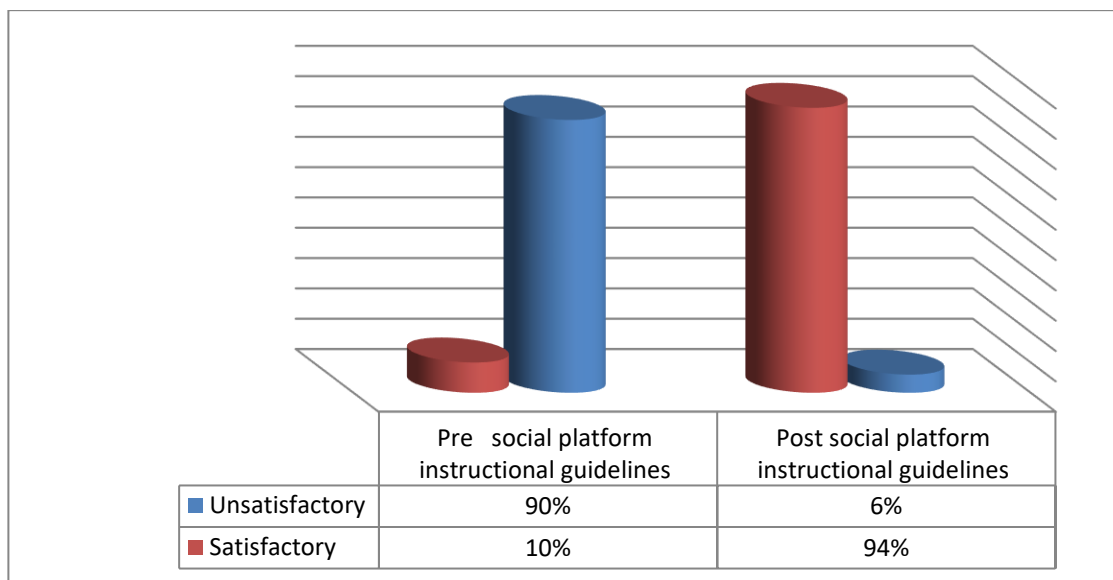


Figure (2): Total Mothers' Knowledge Level regarding Alport Syndrome Pre and Post-Social Platform Instructional Guidelines (n=300)

Table (3): Comparison between Mean Scores of Future Anxiety among the Studied Mothers pre- and Post Social Platform instructional guidelines (n=300)

Future Anxiety items	Pre-social platform instructional guidelines	Post social platform instructional guidelines	t-test	P-value
Fear and worries about the future	7.3 ± 2.4	4.2 ± 2.1	7.44	0.0001**
Despair of the future	10.5 ± 3.1	4.3 ± 2.4	11.55	0.0001**
Worry thinking about the future	9.7 ± 3.2	7.4 ± 1.2	3.77	0.001**
Health and death anxiety	6.7 ± 3.2	3.8 ± 2.2	6.66	0.0001**
Future anxiety related to the problem	6.3 ± 2.5	3.5 ± 2.2	6.33	0.0001**
Total future anxiety	40.01 ± 9.3	24.3 ± 9.4	8.76	0.0001**

**Highly statistically significant differences

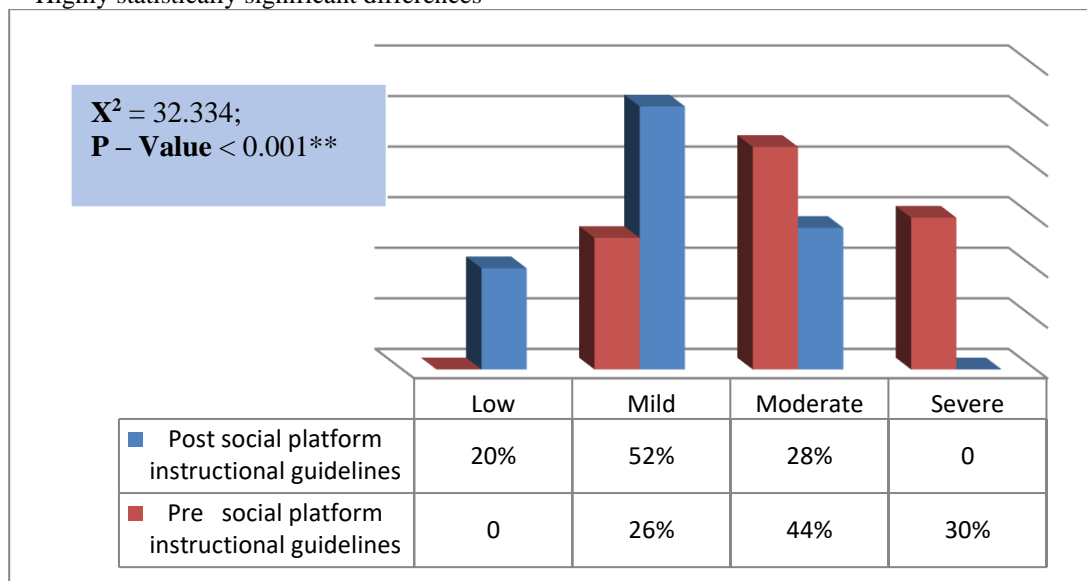


Figure (3): Total Future Anxiety among the Studied Mothers Pre and Post Social Platform instructional guidelines (n=300)

Table (4): Correlation between Total Knowledge and Future Anxiety among the Studied Mothers and their demographic data (n= 300).

Items		Knowledge	Future anxiety
Mothers' age	R	-.133-	.186
	P – value	.353	.188
Mothers' educational level	R	-.563	-.042-
	P – value	.0001**	.772
Mothers' occupation	R	.074	-.367
	P – value	.608	.007**
Mothers' residence	R	.046	-.508
	P – value	.743	.0001**

** . Correlation is significant at the 0.01 level*

Table (5): Correlation between Total Knowledge and Future Anxiety among the Studied Mothers Pre and Post Social-Platform instructional guidelines (n= 300).

Items	Variables		Pre-social platform instructional guidelines	Post social platform instructional guidelines
			Knowledge	Knowledge
Pre-social platform instructional guidelines	Future anxiety	R	-0.092	0.157
		P – value	0.539	0.216
Post social platform instructional guidelines	Future anxiety	R	0.843	-0.663
		P – value	0.179	0.016*

*. Correlation is significant at the 0.05 level

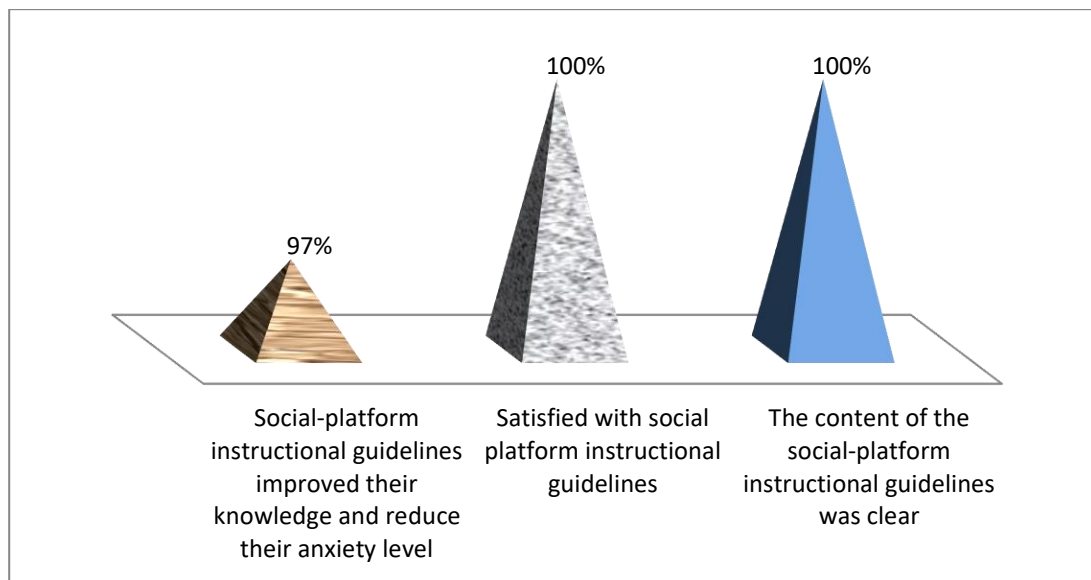


Figure (4): Mothers distribution concerning satisfaction with Social-Platform instructional guidelines (n= 300)

Discussion:

Alport syndrome is a hereditary condition that affects the kidneys' basement membrane and can also affect other organs like the eyes and inner ear's cochlea. It is typified by mutations that result in anomalies in the collagen found in the basement membrane, which is essential to the kidneys' filtration function. Chronic renal disease is frequently the outcome of these anomalies, which cause increasing kidney damage. In certain instances of Alport syndrome, sensorineural hearing loss may result from the aberrant collagen's impact on the inner ear's cochlea. Additionally, visual issues may arise due to alterations in the ocular lens known as anterior lenticonus (Cosgrove, 2022).

According to Dong and Bouey (2020),

psychological problems such as anxiety, tension, and worry regarding illness on social media can be brought on by chronic diseases. According to Irvine et al. (2020), social-platform interventions have been demonstrated to be clinically helpful in lowering anxiety in a variety of conditions, and digital care and the internet can effectively carry them out. The results demonstrated that social media-based guidelines were beneficial in increasing mothers' awareness of and lowering their anxiety levels related to Alport Syndrome. So, the study aimed to evaluate the effect of social-platform instructional guidelines on pediatric mothers' knowledge, and anxiety regarding Alport Syndrome. Based on the results, most of the mothers in the study were in the 20–30 age range. According to the researchers, the reason for the moms' psychological problems,

including worry, maybe that they were too young and lacked sufficient expertise.

The results of this study showed that less than three-quarters of the mothers who were the subject of the survey said that doctors were the primary source of their knowledge on Alport Syndrome. There is proof that the mothers get their information from a trustworthy source.

With a highly statistically significant difference in the total knowledge scores, the current study's findings demonstrated that the mothers under investigation knew less about Alport Syndrome before and after social platform instructional guidelines. According to the researchers, the effectiveness of the execution of instructional guidelines and its benefits demonstrate this. Also illustrates the significance and efficacy of implementing such recommendations for mothers with reference to Alport Syndrome.

The present study's findings demonstrated that, before the social platform educational guidelines, the majority of the mothers under investigation knew insufficiently about Alport Syndrome. According to the study, this demonstrated the need to implement social media platform educational standards for mothers to enhance their understanding. In addition, the current study reveals that mothers' understanding of all Alport Syndrome items has improved in a highly statistically significant way following social platform instructional recommendations. According to the study, this may be because the moms received current and intelligible information regarding Alport Syndrome throughout the program. This finding is consistent with that of **Matsuda and Kohno (2016)** and **Ekhtiari et al., 2017**), who found that education improved participants' knowledge about the illness.

This result matched Fan et al.'s (2020) "theory of KAP," which states that a change in health behavior results from practicing and possessing the appropriate information. Additionally, a recent study by **Rana et al. (2020)** discovered a connection between successful illness prevention, control, and promotion and enough personal knowledge. According to a study done by **Ricardo et al.**

(2018), bad health and maladaptive disease prevention behavior are associated with a lack of knowledge.

When contrasting the mean score of the mothers' overall future anxiety before and after they adhered to the social platform's instructional guidelines, there was a substantial statistical difference. The researchers believe that this may be the case because moms are not familiar with the issue and are concerned about the potential consequences for their children in the event that they get sick.

The results of this study may suggest that mothers' chronic illnesses led to significant stress in every area of their lives, including the health of their children, which excited them greatly. Others were worried or anxious about their kids getting infected, but after learning enough about Alport Syndrome via social media platform training materials, their worries and anxieties subsided. Increased knowledge of Alport Syndrome and the stress-reduction benefits of instructional guidelines may be connected to this. Based on available scientific evidence from chronic conditions, mothers' mental health benefits from online psychological treatments, like Telehealth, are significant (**Galea et al., 2020**).

The results of this study showed that a statistically significant difference regarding the mean score of fear and future worries among the mothers under study decreased after following the social platform instructional guidelines as opposed to before.

The results of the current investigation showed that, before social platform instructional guidelines, less than one-third of the women under study experienced extreme levels of future anxiety. According to the researchers, this might be the consequence of a high degree of stress; moms are worried about their children, unaware of the safety precautions for Alport Syndrome, and unprepared for the abrupt shift in their children's fashion (**Xinhua 2020**). The fact that only 3% of participants had severe future anxiety after following the social platform instructional guidelines demonstrated the effectiveness of these recommendations in achieving the current study's goal.

According to these findings, the moms in the study had less overall future anxiety after following the social platform's instructional guidelines than they did before the treatments. These results may be explained by the absence of medical facilities in the nation, the difficulties in treating the condition, and mothers' worries about their kids getting sick. Mothers may feel emotionally distressed by their children at home, especially if they become ill (CDC, 2020). The results of this investigation are consistent with those of a study conducted by (Pajari & Sinkkonen, 2020).

A previous study on "Future anxiety of the people" in Egypt by Mo'ashi & Muhamed (2022) indicated that students had a considerable level of future concern, which supports the conclusions of this study. In a poll conducted in Turkey by the Mental Health Association (MHA), more than sixty-one percent of respondents expressed increased anxiety about their future (MHA, 2020).

According to the results of the current study, the level of general future fear declined after the session. Given that students now understand the key elements of F.A. and have alternative coping mechanisms, the researchers believe that this may be the result of the positive impact of the instructional guidelines, which led to knowledge improvement and a decrease in stress. A new method of handling stressors during anxious periods and relaxation techniques were also taught to the mothers. They also learned that unknown accepting of life events is associated with F.A.

The current study shows that the mothers' educational level and their knowledge had a moderately negative correlation. Mothers' occupation, residence, and degree of future fear also showed a moderately unfavorable correlation. High mean scores of the mothers' future fear are associated with their residency, especially in rural areas, and their pre-social-platform instructional guidelines. This could explain why mothers in rural areas are more stressed due to resource deficits and a lack of awareness from social media. Additionally, rural and urban areas have different cultures,

values, and beliefs. Additionally, moms' work was associated with a significant level of worry. One possible explanation for this outcome is that working women may get more anxious about their young children being left alone when they are away from home for extended periods.

According to the current study, there was a moderately negative link between the mothers' knowledge and practices and their future worries after following the social platform psycho-instructional guidelines. According to the experts, a lack of information results in subpar habits that heighten future anxiety over the unknown.

According to the current study, all of the mothers who were the subject of the study said that the social platform instructional guidelines were clear and that they improved their knowledge and practices while lowering their anxiety levels. The majority of the mothers also expressed satisfaction with the guidelines. This outcome is indicative of the effectiveness of implementing the educational recommendations, which satisfied the mothers' requirements and gave them the knowledge they needed to manage this illness. Also shows how well the study's goal was achieved.

Online or internet-based psychotherapy for moms has demonstrated potential in treating and reducing anxiety, both with and without the help of a therapist (Jolstedt et al., 2018). Additionally associated with a decreased risk of anxiety were yoga, meditation-based programs, online conversation with friends, and online psychology courses (Fenfen et al., 2020).

Similarly, a study by Melnyk et al. (2019) discovered that therapist-led online therapy, a skill-training program based on cognitive behavioral therapy, relaxation techniques, art-based programs, support services, clinician-led mental health, and psychosocial services all successfully lower anxiety and mental health problems in mothers.

Conclusion:

Based on the current study's findings, the research concluded that social-platform

instructional guidelines implementation regarding Alport Syndrome positively impacts mothers' anxiety levels and increases their knowledge.

Recommendations:

Based on the current study's findings, the following suggestions were made:

- Offer mothers a carefully thought-out health education program to increase their knowledge of Alport Syndrome.
- It is crucial to encourage and aid in psychological adjustment by reinforcing potential interventions.
- Pediatric Outpatient Clinics should develop and distribute brochures and booklets that provide adequate information about Alport Syndrome and preventative measures to all mothers and caregivers of children.
- Replication of nursing intervention of this study on a larger sample

Limitations of the study:

One of the two drawbacks of the study was that in-person interviews with the mothers were not possible. The online nature of the study resulted in sample bias and an inaccurate representation of the entire mother population, as it only included educated women with internet access.

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