

# Health Awareness Campaigns and Their Role in Promoting Awareness of Rare Diseases

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## KEYWORDS:

Rare disease, Orphan diseases, Awareness campaigns, Health awareness, Dependency theory.

## ABSTRACT:

Over recent years, rare diseases affected people's lives, families, and jobs, and their cumulative effects on systems of health and social care have gained more attention.

The lack of health awareness of rare diseases and the scarcity of the expertise is translated into delayed diagnosis and difficult access to appropriate health care. In the past few decades, increased awareness of rare diseases has led to improvements in diagnosis, treatment which led to change in thinking and in behavior towards rare diseases.

The research is trying to provide a response to the question of What is the role that awareness campaigns play in raising awareness of rare diseases and do they provide the necessary information to the target group , and aims to clarify the importance of using awareness campaigns as an effective tool that can and raise awareness of rare disease nature, characteristics, and how to diagnose it, so The research supposes that understanding the role played by health awareness campaigns helps to speed up the diagnosis of the rare diseases.

In addition, the researcher followed both descriptive and the applied approach by presenting three rare disease awareness posters and a questionnaire as an attempt to develop the effectiveness of awareness campaigns To Improve and speed up diagnosis and care of rare diseases and found out that the increased knowledge and understanding caused by awareness campaigns rare diseases give society the reasons and how rare diseases occur and change the way we view and how to treat disease.

## Introduction

Most rare diseases are genetic disorders including congenital defects, auto-immune disorders, congenital malformations, toxic and infectious diseases, and rare cancers. even though some rare diseases are compatible with a normal life if diagnosed on time and professionally managed. For thousands of people with rare diseases, the greatest obstacle to improving quality of life are misdiagnosis and non-diagnosis. (European Commission (EC), 2020)

Compared to other diseases, rare diseases can lack similar levels of interest amongst the doctors and medical communities. Most of these rare diseases receive little attention because they affect small number of patients worldwide. Also, patients are not the only ones affected by rare diseases. Families, friends, caretakers, doctors, and society are all impacted by these diseases.

the lack of information about many rare diseases is a major obstacle. Often, to obtain answers, patients scour the Internet for assistance with diagnosis, treatments, specialists, and information on the Symptoms and treatment methods of rare disease. (Christian, June 2013)

Therefore Rare disease awareness campaigns play a pivotal role in society, as they are responsible for transmitting cultures and knowledge, and it is one of the most important means that contribute to spread health awareness, in addition to being a primary source of information about rare diseases and modifying attitudes and behavior of patients and society towards this diseases to accept and deal with them, is often disseminated through many different advertising media including advertisements in social media, newspapers, magazines, outdoor, radio, tv, mail advertisements, event marketing and email marketing. (Danaher, 2010), so the importance of the research becomes clear by Consolidating the importance of rare diseases health awareness campaigns as one of the basic means of promoting health awareness within the society and studying how to use them in the manner that contributes to raise the level of health awareness.

## Theoretical Framework:

### First: Definition and identification of rare diseases:

In the European Union, a disease is defined as rare when it affects fewer than five in 10,000 people. Although there are many rare diseases (RDs), each one is rare in and of itself. More than 7,000 diseases are

classified as rare. Most of them are genetic, have a chance of becoming deadly, and have a long-term impact on people's lives from early to late in life. Typically, neither the patient's lifestyle decisions nor any visible environmental variables may cause rare diseases.

### 1. Definition of Rare Diseases (orphan diseases) (RDs):

There is no universal or standard definition of rare disease, and it is impossible to prescribe threshold prevalence rates to classify a disease condition as rare in the absence of epidemiological data on diseases that are rare countries. Until such data are available, and the World Health Organization (WHO) defines a rare disease based on prevalence data, the term rare diseases shall be defined as follows:

- a life-threatening or chronically debilitating disease that affects five people or fewer in 10,000 and requires special, combined efforts to enable patients to be treated effectively. (Howe, Earl, and others 2013),
- Rare diseases are a group of diseases with exceptionally low incidence and prevalence.
- The Council of the European Union in its Recommendation identifies rare diseases as a serious public health problem and “a threat to the health of EU citizens, insofar as they are life-threatening or chronically debilitating diseases with a low prevalence and a high level of complexity. (Iskrov ,Georgi and others, April 2011).

Confusion and discrepancies can arise from the usage of language with varied definitions. Most definitions, as mentioned above, seem to take disease prevalence into account, but additional criteria, such as disease severity, if the condition is life-threatening, whether there are other treatment alternatives available, and whether it is heritable. (BYMBE, April 2018)

### 2. The different effects of rare diseases on patients:

Rare diseases have several impacts and effects on patients' lives, including:

- Emotional Impact: There are additional emotional consequences like worry, stress, and anxiety, as there are with any disease. These burdens are compounded by uncertainty, the lack of available information and resources for many patients with rare diseases and their caregivers.
- According to the study conducted by Christian J Hendriks entitled (Rare Disease Impact Report: Insights from patients and the medical

community) in 2014 showed that informing people with rare diseases about their disease led to a variety of reactions, including depression, anxiety, and tension. It also isolated them from friends and family and reduced social engagement.

- exaggerated Financial Costs of Care: Patients and caregivers dealing with a rare disease have a significant financial burden due to the long diagnostic process and continuous clinical care.
- Quality of Life: When compared to a person who is otherwise healthy, as well as to those who have more common, significant conditions, patients with rare diseases have worse overall quality of life than healthy people. (Christian, June 2013)

### **Second: Rare disease awareness campaigns:**

Awareness campaigns have a significant importance in promoting desirable human behaviors. The importance of these campaigns increases with the increase in the change in the surrounding environment and the development of technology, which requires the planning and implementation of awareness campaigns to educate individuals, and given the importance of awareness campaigns in changing behaviors, many researchers have been interested in the concept of awareness campaigns and provide many definitions to clarify this concept according to their interests and the nature of their specializations, in addition to the jobs that The campaign and the goals to be achieved.

Awareness campaign also serves to educate the audience about a certain topic related to a certain society It aim to raise public awareness of a certain problem by providing convincing facts and highlighting the damage that may result from a certain undesirable behavior to direct the audience towards a more favorable one (Mohamed, 2019)

In addition to There is a long history of inconclusive evidence on the success of awareness campaigns in changing behaviors and specifically changing public health behaviors. (Jeanette Kane Ziegenfuss, November 2008)

#### **1. Definition of health awareness:**

Health awareness is an essential feature of societies in the current era that requires knowledge, motivation, to access, understand, evaluate, and apply information to manage health and interact with services related to health and wellbeing.

The term health awareness has appeared in the academic literature since 1974, but it was quite

different from the current understanding of the concept, but with the beginning of the nineties of the twentieth century it began to appear in earnest and witnessed significant growth since the initiation of those efforts (Kevin B. Wright, 2012) Many definitions of health awareness and education have emerged, all of which share the fact that health awareness is mainly focused on the behavior of individuals, and health awareness is a broad concept and several definitions have grown, including:

- People's motivation, knowledge, and competencies to access, understand, evaluate, and apply health information to make judgments and make decisions in everyday life related to health care, disease prevention, and health promotion to maintain or improve quality of life.
- Knowledge and competence of people to meet the complex requirements of health operations. (Saif eldin elsayed, soheir 2022)

#### **2. The concept of rare diseases awareness campaigns:**

Awareness campaigns are considered one of the tools that are used in health development, and it is a motivator that pushes the recipient to pay attention and search for more information and encourages him to try to take a certain behavior, it can be defined as following:

- One of the social communication methods that aims to make a certain impact on the target group, which makes us use all means of mass communication with the aim of convincing the masses of a new idea or forming a mental image towards innovative ideas during a certain period.
- A set of organized efforts to change the behaviors, attitudes, and beliefs about the health and environmental conditions of a specific group of individuals at risk for health problems through Various advertising media during a specific period. (Moneira, abd elhadi, 2017)

Hence, the researcher has defined rare diseases awareness campaigns as: a group of organized efforts that seek to make a specific impact on the target group either from patients, doctors, or caregivers, using traditional and digital advertising, with the aim of providing appropriate health awareness to the society and warning them of the dangers of rare diseases, symptoms, and how to deal with them, to reach the optimal health values.

Health awareness campaigns aim to help individuals create a clear picture of the nature of the health situation within the society and develop health awareness for them through the establishment of a healthy culture, in addition to the fact that the lack of health awareness and its decline within societies is considered a “silent killer.” (Saif eldin elsayed, soheir 2022)

### 3. Objectives of Rare Diseases Awareness Campaigns:

Health awareness is one of the goals that awareness campaigns seek to achieve, and it is the goal that societies seek to reach and achieve among their members. The goals of the awareness campaign for rare diseases are determined as follows:

- Establishing certain positive values or spreading important knowledge concepts, such as how to prevent epidemics and rare diseases.
- Clarify the facts and educate citizens about their rights to demand the necessary health care.
- Providing individuals with health information about their communities and knowledge of health problems and rare diseases, the rate of their incidence, their causes, methods of prevention and means of combating them.
- Introduce individuals to health services and facilities that deal and treat rare diseases in their communities and understand the purpose of their establishment and how to benefit from them in an organized and feasible manner.
- An individual's understanding of the health problems caused by rare diseases and ways to solve them, and knowledge of methods to maintain the general health of the individual and society. (Turafy, Aliaa, 2021)



• (MPSI): Mucopolysaccharidosis is a rare disease in which the body lacks or lacks enough of an enzyme necessary to breakdown long chains of sugar molecules. Glycosaminoglycans are these molecular chains. As a result, the molecules collect in various

Fig (1): An awareness social media ad for the rare disease (MPS) • that contains information about the disease. (Online: [www.porterhousemedical.com](http://www.porterhousemedical.com))

### 4. Importance of Rare Disease Awareness Campaigns:

When dealing with one disease that has an impact on so few people there is often a lack of information which confounds patients and doctors, there is less information available to help determine the standards of care for rare diseases, Therefore, awareness campaigns for rare diseases are so important for the following reasons: (Christian, June 2013)

- Awareness campaigns are a tool to reach the largest segment of the target group with a high concentration, because they consider the means of communication, the locations of the recipient, the use of the best method to influence the target group and achieve the desired effect.
- It is directed to target groups characterized by diversity and difference, and works to change different health trends and behaviors, and this requires a great and continuous effort, as the individual often refuses to change his health awareness, ideas, behaviors thus his beliefs that he acquired from the values and customs of society. (Saif eldin elsayed, soheir 2022)



Fig (2): an awareness campaign that raises understanding of the rare genetic disease which clarified the diversity in the target group to further emphasize the seriousness of rare diseases. (Online: [www.campaignlive.co.uk](http://www.campaignlive.co.uk))

- Health awareness campaigns play a pivotal role in overcoming some of the barriers between complex medical information and the ability of individuals to understand and communicate this necessary health information.

places of the body and result in a variety of health issues. Source: online: <https://medlineplus.gov/>



- Interpret and simplify information for medical professionals and non-professionals that can produce positive changes or prevent negative changes in health awareness of rare diseases and health-related behaviors among many recipients.



Fig (3): An awareness ad that simplifies medical information about the rare disease (CMT)• showing its symptoms such as loss of balance, weakness of the hands and feet, and complete disability. (Online: <https://ecmtf.org/2020-cmt-awareness-campaign/>)

- seeks to reduce the incidence and prevalence of rare diseases by the creation of awareness through an integrated and so all preventative awareness campaign.
- Increase knowledge of importance of premarital, post-marital, pre-conception and post-conception screening and counselling programs to prevent births of children with rare diseases. (Vardhan, Harsh, 2021)
- seldom rare disease physicians see amass sufficient experience in all phases of diagnosis, treatment, and supportive care to become experts on a specific disorder. This leads them to call for an increase in education and support to assist in gathering and sharing rare disease information with each other, and it is an issue that can be solved through health awareness campaigns.



\* Charcot-Marie-Tooth disease (CMT): is are rare disease and a group of inherited conditions that damage the peripheral nerves. Source: [online: www.nhs.uk](http://online: www.nhs.uk)

Fig (4): A complete awareness campaign that encourages meeting and exchange of information between patients and those interested to raise awareness of the rare disease (Rett Syndrome)

- (Online: [www.mmm-online.com](http://www.mmm-online.com)), (Online: [www.pnewswire.com](http://www.pnewswire.com))

### 5. Factors affecting rare disease awareness campaigns:

There are some crucial factors that must be considered and studied well from all sides before heading for awareness raising rare diseases campaigns, which are:

- Political factors: stability of the political environment, government’s attitude towards the health issue, past and present policies influencing health issue, and decisions to face the increasing rate of rare diseases.
- Economic factors: economic growth or recession related to dealing with diseases in general and rare diseases, raising the cost of treatment for some patients due to the lack of companies producing it.
- Socio-cultural factors: population growth, wealth, education, language, religion, health, sources of motivation, lifestyle for patients and their relatives, their culture, environment, and fears.
- Technological factors: innovation, emerging technologies that help in accessing new medical devices and technologies that help in the early diagnosis of rare diseases to receive initial treatment and reduce the number of infected people. (Abd elhady sabry, 2021)

### 6. Advantages of using rare disease awareness campaigns:

- Due to patients' and doctors' inability to figure out the connection between the symptoms—and combinations of symptoms—and the disease itself, many rare diseases might remain undiagnosed for years.
- Awareness campaigns can raise disease awareness and educate patients, their families, and physicians about the symptoms and how to recognize them.
- Patient-directed campaigns, which frequently use social media, disease awareness days, and advertising plans, can undoubtedly assist in the identification of individual patient. This typically occurs when parents, relatives, or other people are exposed to the campaign and connect the symptoms described with a specific patient.

\* Rett syndrome: is a rare genetic condition that impairs brain growth and causes significant physical and mental disabilities. Source: [online: www.nhs.uk](http://online: www.nhs.uk)

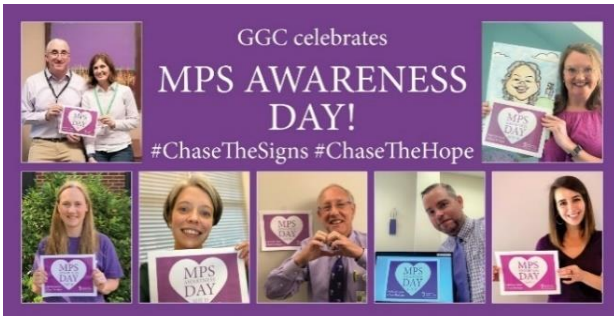


Fig (5): Awareness campaigns on social media that illustrate annual awareness days for rare diseases and (MPS) disease to provide the necessary financial and psychological support. (Online: [www.ggc.org](http://www.ggc.org))

- Over time, awareness campaigns educate both doctors and patients, increase public health awareness of rare diseases, and can significantly speed up the diagnostic process. Examples of these outreach initiatives include International Gaucher • Day, as well as various awareness campaigns website for Hunter syndrome\* (Schmidt, 2018).



Fig (6): Awareness campaigns on the official websites of organizations concerned about Gaucher and Angelman syndrome. (Online: [www.angelman.org](http://www.angelman.org)), (Online: [www.linkedin.com](http://www.linkedin.com)).

### Third: Dependency theory in Awareness campaigns:

\* Gaucher (go-SHAY) disease is caused by a buildup of specific fatty chemicals in specific organs, especially liver and spleen. This can change the functionality of these organs by causing them to expand.

The theory of dependence in awareness campaigns is related to the formation of trends among the target group, and the main idea of the dependency theory is summarized on the ability of communication means to achieve a greater cognitive, emotional and behavioral impact with regard to health awareness of rare diseases, which increases when these means perform the functions of transmitting information in a distinctive way. It is extensive on the causes and symptoms of rare diseases, and this possibility increases its strength in the event of structural instability in society due to conflict and change, and it can be defined as:

- Sources that help provide information or news related to the health field and those interested in following it.
- A group of ideas that refer to the direct dependence of individuals on the media (Saif eldin, soheir, Ebrahim elsayed, 2022)



Fig (7): Awareness campaign in social media, which works to achieve an emotional cognitive impact to increase positive health awareness of rare diseases. (Online: [www.mitopatients.org](http://www.mitopatients.org))

#### 1. Goals and hypotheses of Dependency theory:

In addition, the idea of changing the behavior, knowledge, and conscience of the target group of patients can become a regressive effect of changing knowledge and awareness of rare diseases in society. Institutions and governments can rely on awareness campaigns on rare diseases to achieve the following goals:

- Understanding: such as knowing the symptoms of a rare disease, its causes, methods of treatment, and obtaining experiences in addition to health understanding through knowledge of reliable

\* Hunter syndrome: is an extremely rare hereditary genetic condition caused on by an ineffective or absent enzyme. Iduonate 2-sulfatase is a body enzyme that is missing in Hunter syndrome. Source: [online: www.mayoclinic.org](http://www.mayoclinic.org)



information about rare diseases and patients, and it means helping patients to discover their abilities, support them for use in interpreting beliefs and special concepts and understanding aspects of rare diseases in general.

- **Orientation:** which means the behavior of the society and the medical staff in a manner consistent with social standards and the use of awareness campaigns to guide society members, especially those close to patients, and to make sound behavioral decisions, in addition to interaction that includes ways of behavior and behavior towards others, especially patients.
- **Entertainment:** It includes isolated entertainment such as rest and relaxation, as the delivery of the awareness message in an attractive and positive way reduces the severity of fear of diseases and tension that afflicts patients.

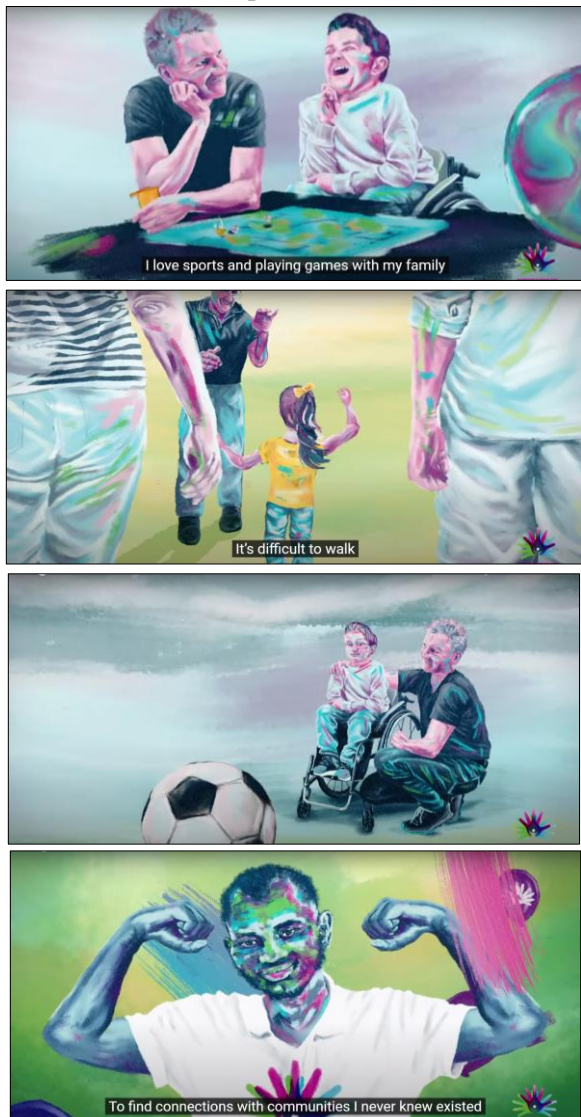


Fig (8): Awareness tv ad about rare disease day in attractive colorful design. (Online: [www.rare diseaseday.org](http://www.rare diseaseday.org))



Fig (9): An awareness campaign through social media, characterized by an attractive and positive design to raise awareness of the International Day of Rare Diseases. (Online: [www.rare diseaseday.org](http://www.rare diseaseday.org))

Dependency theory of awareness campaigns relies on a set of assumptions, which are:

- The impact of awareness campaigns ranges between strength and weakness, depending on the surrounding circumstances and previous experiences of society members with rare diseases.
- The interaction of the recipient with the awareness campaigns are affected by what the individual has learned from the society and his previous experiences, and the recipient is affected by what happens because of being exposed to the various awareness advertising messages.
- it is highlighted in its ability to provide the necessary information, educate patients, and push them to seek early diagnosis and receive appropriate treatment. (Abd elhady, Sabry, 2021)



Fig (10): An awareness campaign that provides necessary information about rare diseases and works to educate patients and encourage them in a positive way to understand and diagnose the disease and resorting to appropriate treatment. (Online: [www.rarediseaseday.org](http://www.rarediseaseday.org))

## 2. The different influences of the dependence theory:

The dependence theory is related to the ability of health awareness campaigns to bring cognitive effects on the individuals who depend on them, which contribute to the formation of their attitudes:

- **Cognitive influences:** a group of influences that contributed to strengthening the theory of dependence in awareness campaigns, as it formed the intellectual trend of individuals and rearranging priorities towards the rare diseases that patients care about, especially those that directly affect them.
- **Behavioral effects:** A group of effects that awareness campaigns contributed to enhancing by promoting a group of healthy behaviors and eliminating another group of them, which leads to an increase in health awareness among individuals.

- **Emotional influences:** mean the feelings and emotions that the patient has about his surroundings, such as emotional apathy or indifference, fear and anxiety, moral support and alienation, and this effect appears when certain information is provided through awareness campaigns. (Saif eldin, soheir, Ebrahim elsayed, 2022)

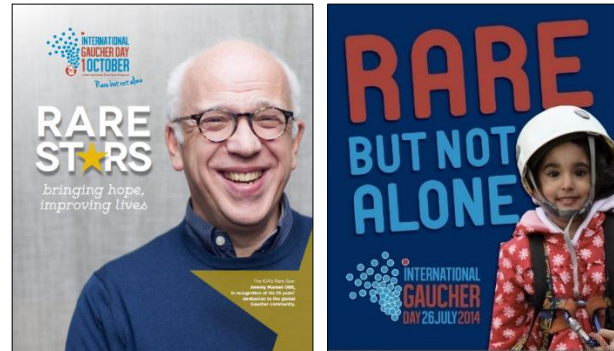


fig (11): Awareness ads tend to influence the emotions and feelings of the patient, provide moral support, and reduce feelings of fear, anxiety, and loneliness for Goucher rare disease patients. (Online: [www.gaucher.org.uk](http://www.gaucher.org.uk))

### Practical framework:

In the theoretical framework, the researcher clarified the concept of awareness campaigns and how to use them to raise awareness of rare diseases, followed by an practical study of three awareness posters applied in different medias and a closed questionnaire aimed at identifying the extent to which the recipient accepts rare diseases awareness campaigns, and their ability to help recipients understand what a rare disease is and accept it positively, which helps to speed up the diagnosis, by asking specific questions related to the basic Knowledge of rare diseases and design standards, 80 individuals were selected as a sample to conduct the research, and the following is a sample of the opinion questionnaire.

#### First: the questionnaire form:

Table (1): the questionnaire form



**(The questionnaire titled rare diseases’ awareness campaigns)**

The researcher seeks to study the role of awareness campaigns in introducing rare diseases, as it proved their effectiveness in clearly influencing raising awareness of rare diseases. Hence, the questionnaire aims to identify the extent to which the recipient accepts campaigns for awareness of rare diseases with an attractive design and its ability to help recipients understand the characteristics of rare diseases and accept it positively, which helps to the speed of diagnosis and receiving the appropriate treatment. The researcher hopes to find cooperation in providing accurate and objective information, as this will undoubtedly lead to a better evaluation of the subject of the study, and thus help in achieving the objectives of the study and produce appropriate proposals. The answers to the questions in the questionnaire are used for scientific research purposes and to achieve the purpose of Research study only.

<b>(1) Demographics:</b>				
1	Name (optional) .....			
2	Age .....			
3	Gender .....			
4	Profession .....			
<b>(2) basic Knowledge of rare diseases:</b>				
		Yes	No	May be
1	Do you or one of your relatives have a rare disease?			
2	Do you have any information or knowledge about rare diseases?			
3	Do you find rare diseases a mysterious and frightening disease that cannot be dealt with?			
4	Are you aware of the symptoms and complications of rare diseases?			
<b>(3) design standards:</b>				
1	Did the awareness ads provide useful information regarding rare diseases?			
2	Do you consider the design positive and attractive and help the recipient accept the idea of rare diseases?			
3	Did the awareness ads help the recipient understand the nature of rare diseases?			
4	Does awareness ads encourage patients with rare diseases to quickly diagnose and receive appropriate treatment?			

**Second: The results of the questionnaire:**

(1) Demographics: the results were as following:

- Age: Less than 30 years old represent 65%, between 30-50 years old represent 25%, over 50 years old represent 10%.
- Gender: Males represent 45%, and females represent 55%.

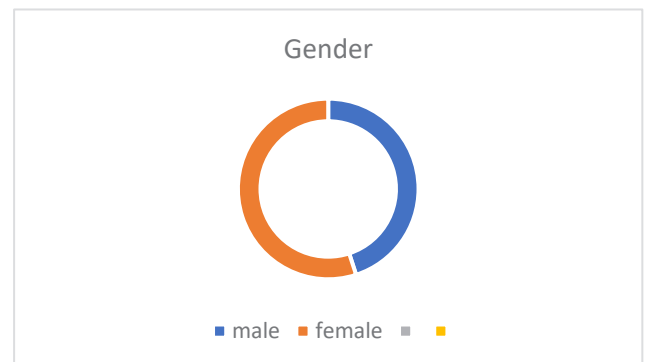
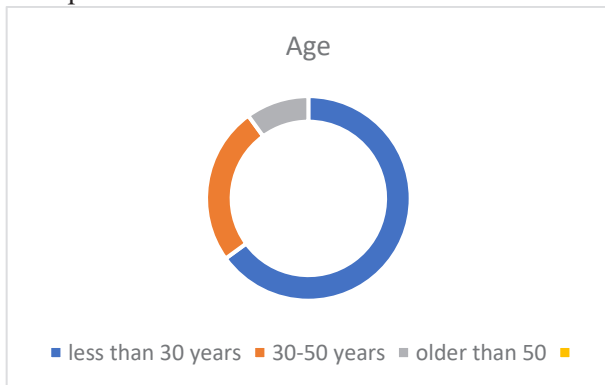


Fig (12): the percentage of age and gender in the questionnaire.

(2) Basic Knowledge of rare diseases: the results were as following:

- first question: Do you or one of your relatives have a rare disease?

The results of the sample varied and were as follows: Yes by 3%, No by 75%, and maybe by 22% because of

the lack of information about the nature of rare diseases.

- second question: Do you have any information or knowledge about rare diseases?

The results were different depending on the cultural background and the abundance of medical awareness of the sample, and they were as follows: yes by 30%, no by 60%, and maybe 10%.

- third question: Do you find rare diseases a mysterious and frightening disease that cannot be dealt with?

The results were as follows: yes by 75%, no by 15%, and maybe 10%. The fear of rare diseases was the result of a lack of health awareness and correct information available about the nature of rare diseases

- fourth question: Are you aware of the symptoms and complications of rare diseases?

The results were expected due to the lack of health awareness related to rare diseases as follows: Yes, by 35%, No by 60%, and maybe 10%.

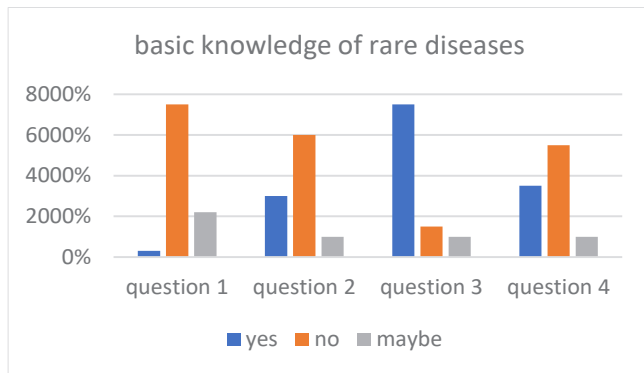


fig (13): basic knowledge of rare diseases questionnaire results diagram.

- (1) Design standards: the results were as following:  
**First applied design.**

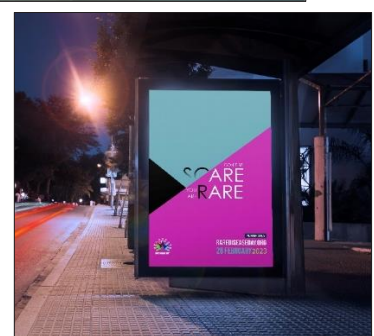
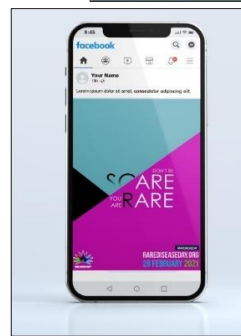
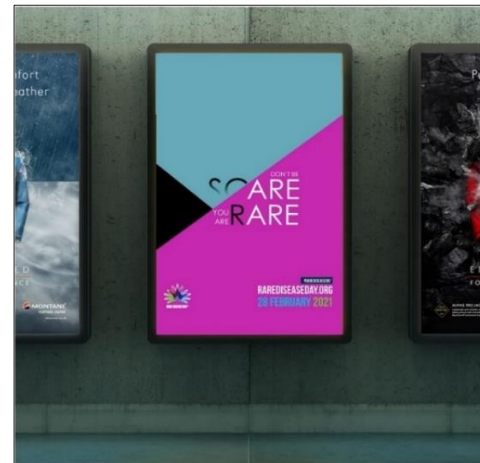
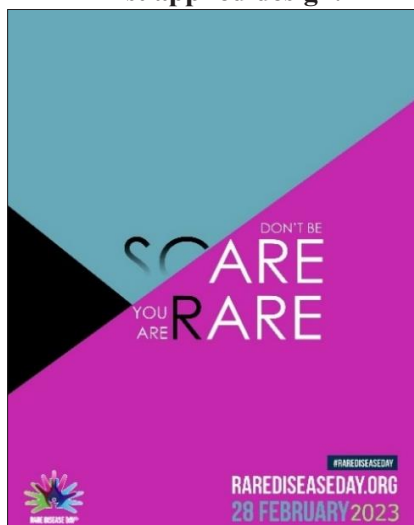


fig (14): first rare diseases awareness design and its application in different medias.

Table (2): Description of the design idea of the first applied design.

<b>Idea of design</b>	The idea of the design is to encourage patients of rare diseases to defeat their fear and increase their awareness of the nature of the rare disease, with the researcher's tendency to use colors that suggest joy and positivity in the design to help the awareness message to be delivered quickly, easily and emphasize the importance of accepting and dealing with the rare disease, while applying the design to Many different advertising medias to clarify the possibility of applying the campaign in many places and repeating it to help spread the idea.
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- First question: Did the awareness ads provide useful information regarding rare diseases?

The results were: Yes 25%, No 55%, maybe 20%

- Second question: Do you consider the design positive and attractive and help the recipient accept the idea of rare diseases?

The results were: Yes 66%, No 12%, maybe 22%

- Third question: Did the awareness ads help the recipient understand the nature of rare diseases?

The results were: Yes 41%, No 13%, maybe 46%

- **Fourth question:** Does awareness ads encourage patients with rare diseases to quickly diagnose and receive appropriate treatment?

The results were: Yes 57%, No 17%, maybe 26%

**Second applied design**

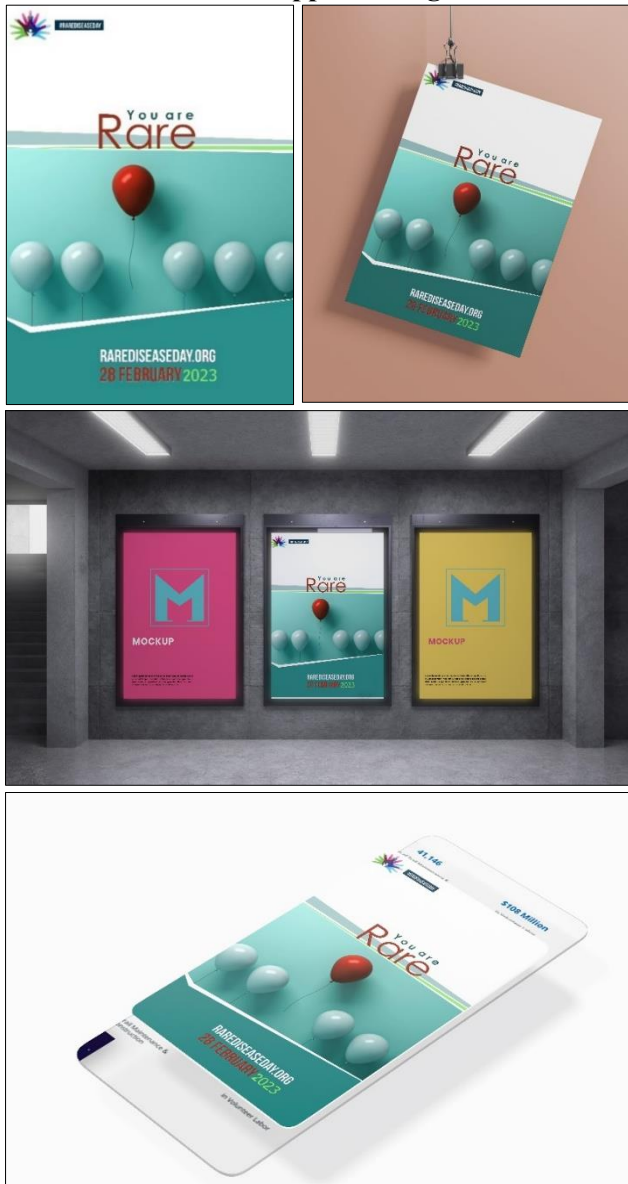


fig (15): second rare diseases awareness design and its application in different medias.

Table (3): Description of the design idea of the second applied design.

<p><b>Idea of design</b></p>	<p>The idea of design can be summed up in emphasizing the difference between patients with rare diseases and the rest of society in a positive and non-repulsive way through the use of an image that shows the difference in a visually attractive way with the use of colors that give a sense of joy and happiness. And</p>
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	<p>the use of the slogan (you are rare) to emphasize the meaning of their distinction and difference and to help them positively accept the rare disease as apatient.</p>
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- **First question:** Did the awareness ads provide useful information regarding rare diseases?

The results were: Yes 42%, No 21%, maybe 37%

- **Second question:** Do you consider the design positive and attractive and help the recipient accept the idea of rare diseases?

The results were: Yes 78%, No 8%, maybe 14%

- **Third question:** Did the awareness ads help the recipient understand the nature of rare diseases?

The results were: Yes 52%, No 19%, maybe 29%

- **Fourth question:** Does awareness ads encourage patients with rare diseases to quickly diagnose and receive appropriate treatment?

The results were: Yes 81%, No 7%, maybe 12%

**Third applied design.**

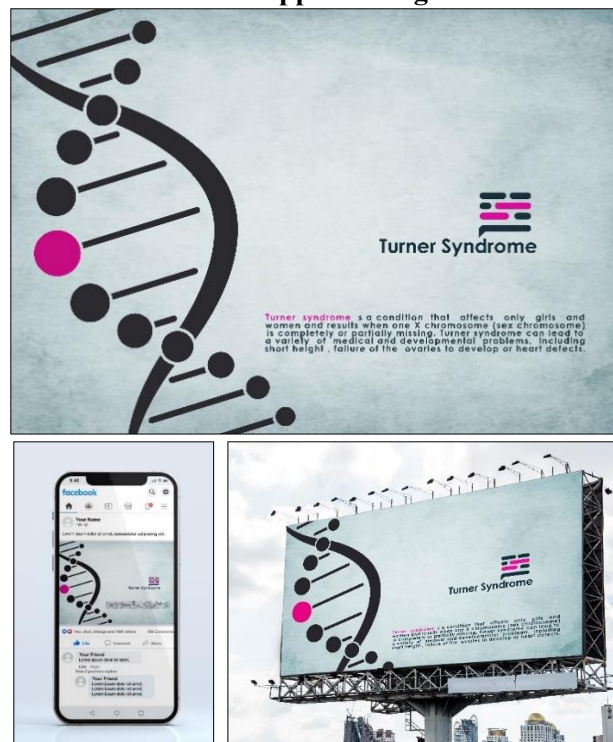


fig (16): third rare diseases awareness design and its application in different medias.

Table (4): Description of the design idea of the third applied design.

	<p>In this design, the researcher focused on providing the recipient with information about a specific rare disease, Turner syndrome, which affects women and girls, when one (X chromosome) is completely or</p>
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<b>Idea of design</b>	partially missing. Turner syndrome can lead to a variety of medical and developmental problems, the researcher cleared the idea by using the shape of the chromosome and employing the pink color in it and mentioning a little data about the disease and explaining its nature, which helps patients to identify it and direct to receive appropriate treatment.
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- **First question:** Did the awareness ads provide useful information regarding rare diseases?

The results were: Yes 78%, No 8%, maybe 14%

- **Second question:** Do you consider the design positive and attractive and help the recipient accept the idea of rare diseases?

The results were: Yes 63%, No 14%, maybe 23%

- **Third question:** Did the awareness ads help the recipient understand the nature of rare diseases?

The results were: Yes 89%, No 4%, maybe 7%

- **Fourth question:** Does awareness ads encourage patients with rare diseases to quickly diagnose and receive appropriate treatment?

The results were: Yes 54%, No 9%, maybe 37%

**Hence, the assembled statistical results to answer the questions related to the Design standards are as follows:**

- **First question:** The results were: Yes 48%, No 28%, maybe 24%
- **Second question:** The results were: Yes 69%, No 11%, maybe 20%
- **Third question:** The results were: Yes 60%, No 13%, maybe 27%
- **Fourth question:** The results were: Yes 64%, No 11%, maybe 25%

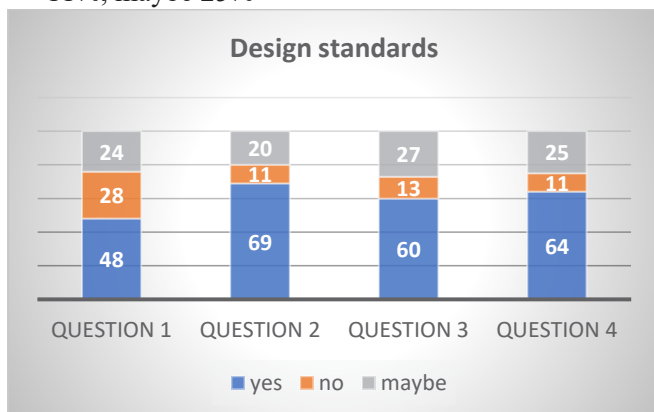


Fig (17): the assembled statistical results to answer the questions of design standards diagram.

### Conclusion:

Although only a small percentage of individuals and families are affected by each rare disease, when considered together, they pose a significant health cost on society. Patients, doctors face unique obstacles because of rare diseases. They also pose unique difficulties for the biopharmaceutical firms creating novel medicines for patients.

The study of uncommon illnesses is a complicated and diverse area. due to the constant detection and reporting of rare new disorders and diseases. The discipline is still in its nascent stage, except for a limited number of rare diseases, where considerable progress has been made. Doctors and researchers were unaware about rare diseases for an exceptionally long time, and there was little real study done on issues related to the field until lately.

Such delays result in increased disease morbidity and mortality rates. Hence, rare diseases are typically associated with significantly larger burdens on the patients. The quality of life and outcomes of patients must be improved by accelerating the diagnostic process. The society must deeply understand the typical "patient journey" and the patient's interactions with GPs and specialists along the way. Such an understanding will, among other things, help countries to identify strategies for overcoming the awareness problem.

As Every awareness campaign's goal is to start and nurture change, whereas awareness campaigns are a collection of coordinated acts that deliver messages that are specific to a concept or goal. Its success depends on the interaction it has generated in support of that aim, so it is important to take Serious steps towards increasing awareness of rare diseases and methods of diagnosing and treating them through awareness announcements because of their positive impact in helping patients and their companions and even the medical staff, if necessary, in realizing the extent of the disease, its symptoms and effects, in addition to its ability to reduce the sense of fear and alienation from the nature of rare diseases as a medical field It is new and does not contain enough specialists to deal with the disease through an attractive design that deals with the disease in a positive way, as awareness advertisements have the ability to encourage patients and related parties to increase understanding and thus speed diagnosis and resort to treatment and avoid complications of the disease.

### Results:

The study confirmed the vital role played by awareness campaigns for rare diseases among different segments of society, and the existence of a correlation between rare disease awareness campaigns and the prominent level of health awareness among members of the society.

Rare disease awareness campaigns help provide information and interesting facts for the limited campaign time, in addition Raising awareness of rare diseases and providing the necessary information through awareness campaigns helps patients understand the nature of rare diseases, help quickly diagnoses, and receive appropriate treatment.

We can confirm that the positive and attractive design of awareness campaigns for rare diseases works to attract the attention of the target group through the distinctive design and how to formulate the awareness message. It also helps patients and those around them to accept the disease, including increasing the rates of receiving.

The small number of doctors who specialize in rare diseases, and the small number of patients with it and their dispersal in different geographical places makes it difficult to control the disease and perform sound statistical procedures, which calls for resorting to awareness advertisements to raise health awareness for its high ability to spread and reach the target group through various advertising means

Developing the awareness campaign message in line with the target group for these campaigns, focusing on the benefits of the campaign and its repetition to consolidate of the awareness message, in order To improve diagnosis and care in the field of rare diseases, appropriate identification needs to be accompanied by accurate information, provided Through awareness announcements that include necessary information to raise health awareness of rare diseases.

The research recommends that Doctors must get training to make early and accurate diagnoses, diagnostic modalities must be standardized, newer diagnostic and treatment instruments must also be developed, and it is critical to Provide the necessary information that helps patients keep up with the latest methods of treatment, control, and diagnosis of rare diseases, especially considering the rapid development of rare diseases facing society and the speed of rare disease spread.

Further research should be done on the impact of rare diseases on both patients with treatable rare diseases and those with ultra-rare conditions where there are not any treatments available and use awareness campaigns to clarify the differences between them, and it is important to pay more attention to rare disease health campaigns, which aim to raise health awareness in the society.

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