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Investigation and Research on Awareness of Rare Diseases in China

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Abstract: Awareness campaigns have been a hot topic for many psychological and physical illnesses, and utilizing awareness campaigns, many donations have been gathered to help those targeted by the awareness campaign. However, rare diseases have been left out of this category, making awareness campaigns more needed than ever in this overlooked field. This paper aims to understand the current situation of the awareness of rare diseases in China through online surveys, so as to determine whether it is necessary to carry out awareness campaigns and to put forward targeted suggestions. Through this study, it can be found that only 1 in every 200 people knew the answers to one of the survey questions, meaning that only 1 in every 200 people had systematically learned about rare diseases in the past. Other academic articles were reviewed to give recommendations to those hosting awareness campaigns to improve awareness campaign results.

Keywords: Rare Diseases, Online Surveys, Awareness Campaigns

1. Introduction

Rare diseases, as defined by *the Orphan Drug Act*, are diseases that affect less than 200,000 people in the United States. The European Union defines them as diseases that affect fewer than 1 in 2,000 people. Rare diseases have not been at the center of attention of the public. But a similar group of diseases, cancer, has three times the average number of searches on Baidu, a Chinese search engine, than rare diseases. There has been barely anything in the research domain on the awareness of rare diseases as of now, so there is missing information on the said topic. And, though there have been "cancer awareness campaigns", there haven't been many rare disease campaigns. As there is a lack of research within this domain, and no research has been conducted on rare disease awareness in any country, the fame of said community is lacking, causing there to be missing personnel within this domain.

This paper aims to find the number of people who know what rare diseases are in China through an online survey, as well as some basic information about rare diseases in the context of China. This paper's topic is on rare disease awareness in China, and to increase the awareness of the rare disease domain in the future. This survey was conducted online, with at least one person from each province present. With an increased awareness of the rare disease community, in the future, people may be willing to choose jobs related to the rare disease community.

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2. Literature Review

Rare diseases have been a missing domain of interest for the public. There are, however, similar surveys on the awareness of other health problems that can be taken into consideration.

A study conducted among residents in Beijing, China found that lung cancer was the most well-known among gastric cancer, lung cancer, oral cancer, and liver cancer, and among those four, oral cancer was the least heard of, with 60% of participants in the study not knowing what the risk factors of oral cancer was, nor did they know what the symptoms exhibited by oral cancer patients were [1].

Dysphagia is a disorder in which the patients have difficulty swallowing, or in some scenarios, the act of swallowing is impossible. A study conducted by Lindsay McHutchion via an online survey revealed that 71% of non-healthcare workers and 29% of healthcare workers had low awareness levels of dysphagia, confirming that there is limited public knowledge of dysphagia, thus demonstrating a need for an increase in awareness levels in said disorder [2].

Colorectal cancer is defined as cancer that begins in the large intestine. This survey was conducted online by Jin and colleagues, with 562 adult Chinese participants, and this study concluded that public awareness of colorectal cancer was low in the Chinese population [3]. It should be noted, however, that this was a cross-sectional survey study, and the Chinese population cannot be completely represented by said participants, as some provinces have been left out of the survey.

Ma et al. conducted a national survey related to anesthesia with a total of more than 1 million participants, with men accounting for 40.7%, and found that "public awareness regarding anesthesiology and anesthesiologists in China remains inadequate" and that "extensive measures should be undertaken to improve public knowledge of anesthesiology" [4].

Other studies that can be referenced are ones such as Matthaei's report on diabetes, as within it states how increased public understanding can also help management of Type 2 Diabetes Mellitus [5]. Some more would be, for example, Agrawal's presentation on how "the lack of knowledge" may cause unintelligent decision making when faced with "early signs of oral cancer" [6], or Wen-Harn's study with a table detailing "Reasoning, definitions, and implications of the suggested BMI action points for obesity" for better reference during awareness reviews [7]. And finally, McNally's "Should I Have Another?" campaign on alcohol awareness, which details precampaign and post campaign data on drinking as well as the measures taken for the awareness campaign [8].

From these studies, it can be seen that even though cancer gets many more times the attention of the public than rare diseases, the public's knowledge of cancer is still extremely limited. For rare diseases, which obtain roughly one-third the attention of the public given to cancer on average, the public's knowledge of rare diseases is something to be done better.

3. Methodology

This study focused on the overall knowledgeability of the public on rare diseases. This survey was conducted online, with at least one representative from each province in China. The median number of participants from each province is 22.5, with a total of 1167 participants, the minimum number of participants from each province being 1 participant and the maximum being 208 participants. For the questions that had fill-in-the-blank answers, all of the answers were reviewed and wrong answers were sorted as "I don't know".

3.1. Survey Questions

The specific question settings are shown in Table 1. Of the above, questions 1, 2, and 12 were on a scale from 1 to 10, while questions 3 to 5, as well as question 10, had a choice of "I don't know" and a blank to fill in if the responder knew the answer. Questions 6 had the choices of true, false, and "I don't know", while questions 7 and 8 had the choices of never, 1 month ago, 3 months ago, 6 months

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ago, 1 year ago, and 2 years ago. Question 9 had the choices of yes and no, and question 11 was a fill-in-the-blank which could be left blank. All fill-in-the-blank answers that were responded with wrong answers were regarded as "I don't know".

Questions 1, 2, 7, 8, and 9 were included to assess the overall awareness of participants in China on rare diseases. Questions 3, 4, 5, 6, 10, and 11 were included to assess the overall knowledgeability of participants in China on rare diseases. Question 12 was included to see if participants' attitudes toward their knowledge of rare diseases would change after taking the survey.

Table 1: Survey Questions

1	On a scale of 1 to 10, how much do you believe you care about rare diseases?	Hot
2	On a scale of 1 to 10, how much do you think you know about rare diseases?	Knowledge
3	Roughly how many rare diseases are there in the world?	How Many Types
4	When did China release "The First Catalog of Rare Diseases in China"?	When Created
5	How many illnesses have been cataloged into "The First Catalog of Rare Diseases in China"?	When In
6	True or false: rare diseases cannot be treated.	No Medicine
7	When did you last search about rare diseases?	Search
8	When did you last see a news article on rare diseases?	Look News
9	Did you ever forward an article or a piece of news to anyone?	Forward
10	How many people in China are rare disease patients?	How Many People
11	Please name a type of rare disease if you can.	1type
12	On a scale of 1 to 10, how much do you think you know about rare diseases now?	Knowledge2

3.2. Survey Results

Table 2: Overview of Answers to Questions with Definite Answers

Answers	1	0
How Many Types	31	1136
When Created	6	1161
When In	8	1159
No Medicine	386	781
Forward	488	679
How Many People	30	1137
1type	63	1104

Table 3: Overview of Answers to Questions with Definite Answers in Percentage

Percentage	Correct	Wrong
How Many Types	2.66%	97.34%
When Created	0.51%	99.49%
When In	0.69%	99.31%

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Table 3: (continued).

No Medicine	33.07%	66.93%
Forward	41.82%	58.18%
How Many People	2.57%	97.43%
1type	5.40%	94.60%

Table 4: Overview of Answers to Questions without Definite Answers

Answers	Never	>1M	>3M	>6M	>12M	>24M
Search	325	50	84	173	217	318
Look News	511	83	78	129	163	203

Table 5: Overview of Answers to Questions without Definite Answers in Percentage

Percentage	Never	>1M	>3M	>6M	>12M	>24M
Search	27.85%	4.28%	7.20%	14.82%	18.59%	27.26%
Look News	43.79%	7.11%	6.68%	11.05%	13.97%	17.40%

Table 6: Answers to Questions that Have Answers on a Scale of 1 to 10

Answers	Hot	Knowledge	Knowledge 2
Min	1	1	1
Q1	3	3	2
Median	5	5	4
Q3	8	7	7
Max	10	10	10

The survey results are presented in Tables 2 to 6. According to Table 6, the median was 5 for the first question, Q1 was 3, Q3 was 8. The median for the second question was 5, Q1 was 3, and Q3 was 7. However, when the question was repeated at the very end of the survey, the median was 4, Q1 was 2, and Q3 was 7. There was an overall 1-point decrease in the 1 to 10 scale in the median and Q1 after the survey was taken when compared to before the survey was taken.

According to Tables 2 and 3, the third question had 31 correct answers out of 1167 people, or around 2.66 correct answers in every 100 people. The fourth question had 6 correct answers out of 1167 people and the fifth question had 8 correct answers. For questions 3 to 5, unless a person has done specific research on rare diseases, most people would not know about them, even if they are common knowledge in this domain. The sixth question had 386 correct answers, but it was a true or false question, meaning that there may have been people who guessed the correct answer, as it wasn't a fill-in-the-blank question like the others. However, the sixth question is a question that is common knowledge to the public, so that should be taken into consideration as well. The ninth question had 488 people respond with "Yes, I have forwarded an article or a piece of news to someone in the past on rare diseases". The tenth question had 30 correct answers, and the eleventh question had 63 correct answers out of 1167 participants.

Questions 7 and 8 have their data presented in Tables 4 and 5 from the previous page. The seventh question had a median of 6 months and a mean of 9.919 months. The eighth question had a median of 1 month and a mean of 6.786 months.

Overall, the participants demonstrated that they had an extreme lack of understanding of the situation of rare diseases. The worst case was when only 6 people correctly announced the answer to

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WhenIn, which was a fill-in-the-blank question, and the best case was when 386 people responded correctly to the true or false question on NoMedicine.

4. Discussion

As can be seen from Section 3, improving the Chinese population's awareness of rare diseases is an urgent need. In this section, previous awareness campaigns have been discussed.

4.1. Previous Awareness Campaigns

A study on awareness campaigns targeted towards the public by Hélène Dumesnil and Pierre Verger found that though different campaigns had different ways of going about spreading awareness, with different objectives in mind, the results were that campaigns had caused an improvement in public knowledge and attitude, but that "most program evaluations failed to assess the durability of the attitude changes" [9].

Many other studies have also found this problem. For example, an article titled "Increasing the Power of Public Awareness" also stated that more information needs to be known about the awareness campaigns, for example, "tracking changes in attitude, behavior, and patient outcomes" [10]. This paper also went on to raise questions on topics such as how often campaigns need to be repeated to have a lasting impact if the public would become desensitized when faced with many campaigns, and if awareness should be tied to fundraising efforts or undertaken separately [6]. This all should also be taken into consideration for campaigns on rare diseases, especially since rare diseases are not a singular type of disease, but a combination of more than 7000 different diseases, each with their own symptoms.

4.2. Rare Disease Campaigns

Though there have been many rare disease campaigns in China, it should be known that most of these campaigns are not widely advertised or are difficult to actually participate in. Though some rare disease types do have official accounts dedicated to said rare disease, barely anyone would remember that they came across such an article or video elaborating on rare diseases when other types of entertainment await them. However, news stories and articles of the sort stay with people longer, so if the goal of the awareness campaign is to simply tell people that rare diseases exist and that there are people out there with rare diseases who are unable to express themselves due to the lack of public attention, stories from patients would be the easiest approach to grab the public's attention.

Overall, awareness campaigns that want to gain the public's attention should first start with stories that various audiences can resonate with, and from that point on, educate the public once their interests are peaked.

5. Conclusion

From this study, it is known that the Chinese population should be exposed to more information on rare diseases and that most of the people don't know, or care about rare diseases enough to learn in-depth about them. As a personal opinion, the public should start by being educated on what rare diseases are, and with time, rare diseases may become common knowledge, like depression or cancer.

This study can be improved by using a larger database, or an offline survey method, as this survey was done online. This study was done under the pretext that the participants did not search for the answers to the survey questions and that the survey was self-designed. Future research can instead focus on how to solve the lack of awareness, and how to lengthen the time people's attitudes change towards rare diseases and public awareness campaigns in general.

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