A Study on Glaucoma Awareness and the Source of Health Information in a Rural Population of Tamil Nadu

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ABSTRACT

BACKGROUND

Glaucoma causes progressive loss of vision and significantly affects the quality of life. In 2019 World Health Organization reported that glaucoma caused blindness in 4.5 million people and is the second most common cause of blindness worldwide. In India, nearly 1.2 million people were blind due to glaucoma of whom 90 percent remain undiagnosed in the community. The aim of this study is to assess the level of glaucoma awareness and to analyse the source of information that created awareness in a rural community.

METHODS

A community based cross-sectional study was conducted in a village which is an outreach field practice area of our institution in Tamil Nadu, during the month of October 2019. The total study participants were 196 and data was collected by interview method and analysed using SPSS 16v software.

RESULTS

Among 196 respondents 12.2 % were aware of glaucoma, 85 % were aware that it leads to blindness, 38 % had heard about glaucoma from close acquaintances through word of mouth and 3 had undergone glaucoma evaluation in an outreach camp.

CONCLUSIONS

This study concludes that awareness of glaucoma among the rural population continues to be poor. Hospital based awareness activity and word of mouth were the major source of information in our study group. Patients with glaucoma had better knowledge and they would play an effective role in creating awareness. Our study shows that the social media and mass media awareness campaign did not reach the rural population.

KEYWORDS

Glaucoma Awareness, Health Information

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BACKGROUND

Glaucoma causes progressive loss of vision and is difficult to diagnose in the early stage of the disease owing to its silent progression. Quality of life, the indicator of wellbeing, depends on the quality of vison.[1,2] Reduced visual function significantly affects Health-related quality of life (HQOL) even during the early stages of glaucoma.[3] The International Agency for the Prevention of Blindness (IAPB),[4] reported an increasing trend in the prevalence of glaucoma and had estimated that 76 million people would be blind due to glaucoma and it would increase up to 112 million in 2040. As per 2019 WHO report, glaucoma caused blindness in 4.5 million people and is the second most common cause of blindness worldwide.

In India, nearly 1.2 million people were blind due to glaucoma and almost 90 percent remain undiagnosed in the community.[5] In 2004, India adopted 'Vision 2020: The Right to Sight' program which aimed to eliminate blindness by the year 2020. Vision 2020 with a mission to start 20,000 primary eye care units termed as 'vision centres which would provide comprehensive eye care services to the people of India. Primary eye care is directed towards cataract, refractive errors, screening and identifying diabetic retinopathy and glaucoma by training health care workers and providing screening equipments.[6,7,8] In spite of this, the burden of blindness due to glaucoma still remains an immense challenge. In a developing country like India, there is poor utilization of eye care services.[9,10,11,12] Moreover the outreach activities concentrate more on cataract.

The patients with glaucoma are diagnosed for the first time during an opportunistic routine screening in the hospital. By then, most of them would be partially or completely blind in one or both eyes.[9,13] Health seeking behaviour of people in our country is poor, especially in rural areas, hence opportunistic glaucoma screening for all is a distant reality. Moreover, factors like delay in diagnosis and cost of medication contribute to the burden of blindness due to glaucoma.

Lack of awareness and knowledge on glaucoma are considered to be the major barrier in addressing glaucoma blindness.[14,15] Every year the glaucoma week is celebrated in the month of March (10^{th} to 16^{th}) with a specific theme. Glaucoma awareness is created during this week through various activities such as organizing outreach camps, walkathons, issuing pamphlets, spreading message through television and newspapers and organizing lectures to the public. In recent years, social media is being used in glaucoma awareness campaign. In 2019, The International Agency for the Prevention of Blindness,[16] also launched glaucoma awareness campaign in Instagram, Facebook and Twitter with the theme "Focus on Glaucoma." Camps, mass media, social media and awareness lectures have been used as campaign tools in creating awareness of glaucoma.

Despite decades of efforts, blindness due to glaucoma is still on the rise. There is a lacunae that needs to be understood to redefine the approach towards the mission for avoidable blindness. Hence, the aim of our study is to reassess the current status of glaucoma awareness and the source of information that has been effective in reaching the rural community, which would be the first step forward in strategizing our eye care approach.

Objectives

- To estimate the level of glaucoma awareness among the rural population of Tamil Nadu.
- To determine the source of information on glaucoma awareness among the rural population of Tamil Nadu.

METHODS

A community based cross-sectional study was conducted over a period of one month during October 2019, among people in a rural village in an outreach field practice area of our institution in Tamil Nadu. The study adhered to declaration of Helsinki. Study was done after obtaining approval from institutional ethical committee approval from Karpaga Vinayaga Institute of Medical Sciences and Research Centre (IEC.ref.no.KIMS/F/2020/06).

Study Population and Sample

The village has a population of 315, with 166 male and 149 females. We collected data from 196 participants. Sample size calculated was 173, with single proportion-absolute precision-finite population correction. People already diagnosed with glaucoma were excluded from the study with screening questions.

Inclusion Criteria

People aged 18 years and above who attended the camp were included in the study after getting written informed consent.

Study Tool

A semi-structured questionnaire was used, and responses were collected by interview method. The questionnaire included information on demographic profile, awareness, knowledge of glaucoma and also how they acquired or learnt that information, mode of acquiring the source of health-related information etc. Questionnaire was prepared in english and translated in tamil for the interview. Residents and optometrists were trained to conduct interview and collect the response.

Statistical Analysis

The primary data was collected and entered in MS Excel and analysed with SPSS software 16v. Descriptive statistics such as mean, standard deviation, frequency and percentages were calculated and represented as tables and graphs.

1. Have you heard of glaucoma? Yes / No
2. Do you know pressure can affect eye? Yes / No (If aware of glaucoma ask the questions below from 3 to 6)
3. If yes how?
   a. From known person
   b. Television
   c. Pamphlet
   d. Radio
   e. Hospital program
4. Do you know it can run in families? Yes / No
5. Do you know you may go blind due to glaucoma? Yes / No
6. Do you know early intervention prevents progression of glaucoma? Yes / No
7. Do you have television at home? Yes / No
8. Do you have mobile phone with social media account?
9. (Mark as yes, even if anyone is mentioned - WhatsApp, Twitter, Facebook) Yes / No
10. What is your education?
    a. Illiterate
    b. High school
    c. Graduate.
11. Do you read newspaper? Yes / No

Survey Questionnaire for Glaucoma Awareness and Source of Information

RESULTS

Among the 196 study participants majority were females (56.6 %) and there was no gender difference noted in the glaucoma aware group. Table 1 also describes that half of the participants had school level education (56.1 %) and one third were illiterate as well (33.7 %).

Table 2 explains that only around 24 (12 %) of the study participants were aware about glaucoma, among them 6 were illiterate, 15 participants studied till high school and only 3 were graduates. Most of them were not familiar with the term glaucoma, instead they were aware that raised pressure in the eyes affects the vision.

Among the glaucoma aware group, 21 (85 %) knew that glaucoma could lead to blindness. 9 participants knew that it might run in families and only 6 of them were aware that early diagnosis and treatment could prevent the progression of the disease. (Fig. 1)

Table 2 describes that among the glaucoma aware group (n = 24), 50 % (n = 12) had attended hospital awareness campaign programs in nearby hospitals. These participants had better knowledge about glaucoma, than others. Among those who had not attended hospital awareness campaigns, 38 % said that they heard about glaucoma from close acquaintances and patients with glaucoma, through word of mouth. This group knew that glaucoma can cause blindness. Three of them had undergone glaucoma evaluation in an outreach camp. All the participants had access to a television, and majority of them had a mobile phone with a social media account either WhatsApp or Facebook, but none of them mentioned social media and mass media as their source of information.

Gender	Frequency (n = 196)	Percentage
Male	85	43.4
Female	111	56.6
Education		
Illiterate	66	33.7
High school	110	56.1
Graduate	**20**	**10.2**

Table 1. Gender and Educational Status of the Study Population

Awareness of Glaucoma	Frequency (n = 196)	%
Aware group	24	12.2 %
Unaware group	172	87.8 %
Source of Information of Aware Group		
Camp	3	12 %
Hospital programs	12	50 %
Word of mouth	9	37.5 %
Mass Media Accessibility of Study Population		
Television	196	100 %
Newspaper reading	196	100 %
Mobile phone with social Media	187	95 %

Table 2. Awareness of Glaucoma amongst the Study Population

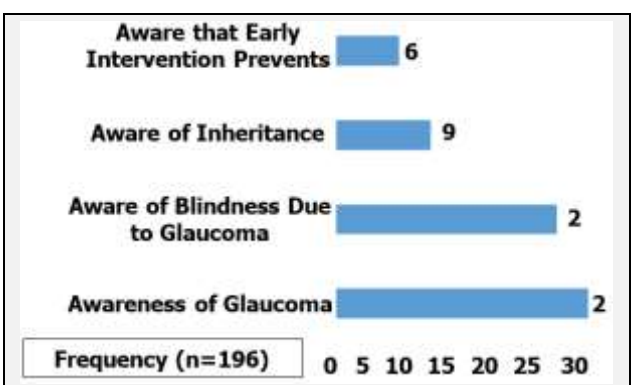

Figure 1. Distribution of Knowledge of Glaucoma amongst the Aware Group

DISCUSSION

Our study was designed to assess the level of awareness of glaucoma in a rural setting, with the main objective of exploring the source of information that was effective in creating awareness.

Most of the participants in our study were not aware of the terminology 'Glaucoma' or the Tamil equivalent 'Kann Azhuththa Noi'. Therefore, we have also included the participants as aware of glaucoma, if they knew about raised pressure in the eye affecting vision.

Awareness of glaucoma in India is poor which ranges from 0.32 % to 13.5 %.[13,17,18,19,20] Poor glaucoma awareness was reported by Parveen Rewri, et al.[11] among rural residents of northern India in 2014 and Nirmala et al.,[19] in the state of Kerala in 2016. Sathyamangalam et al.,[18] documented 13.5 % of study population were aware of glaucoma even in urban area of southern India in 2009. Similarly, in our study only 12 % of the study participants were aware of glaucoma. Therefore, it is evident that, awareness of glaucoma is still poor in India.

Our study did not find any relationship between age and gender; glaucoma awareness is similar to Tenkir et al.,[20] Hennis et al.,[21] Pfeiffer et al.[22]

Education and Awareness

Glaucoma awareness studies in the literature, showed that education provided better awareness and knowledge about a disease.[13,23,24,25] In a study by Parween Rewri et al.[11] education was the only factor associated with awareness of glaucoma. Although, more than fifty percent in our study group had formal education up to high school, it did not effectively translate into health awareness. This observation in our study documents that formal educational qualification cannot be equated to health literacy.

Though we cannot generalize our finding, it is clear that there is a gap in formal education and health education. Shweikh Y,[24] expounded a successful model where school children of a community were trained as health messengers. The children were taught about eye health and its importance and they were rewarded for bringing their family members for eye check-up. This significantly increased the hospital census for eye examination. Therefore we suggest that, incorporating health education at school would be a cost-effective community health intervention and would change health seeking behavior of people.

Word of Mouth

Word of Mouth from close acquaintance and relatives suffering from glaucoma was one of the important source of information in our study. In the studies conducted by Parveen Rewri et al.[11] among the rural residents of Northern India and Dandona R et al.[13] among the urban areas of Andhra Pradesh, 'word of mouth' (WOM) was a significant source of information. Sathyamangalam RV et al.[18] in their Urban Glaucoma Project, had reported that word of mouth from glaucoma patients provide more knowledge when compared to other sources. Influence of word of mouth in health care has been documented by Martin and Sebastian.[25] Word of mouth could sprawl information either in person or on social media. We propose that word of mouth from patients with glaucoma could be a powerful campaign tool in creating better awareness and knowledge of glaucoma.

Hospital Awareness Programs

Every year during the glaucoma week celebrations, hospitals conduct several awareness program. We included hospital awareness activities as a source of information to find out whether these programs had any influence on the health awareness of the community. In our study, the major source of information was from the hospital awareness activities during prior hospital visits. Hospital awareness program as a source of information was not mentioned in any of the previous literature. We recommend that awareness activities should be conducted throughout the year, so that the patients visiting the hospital acquire knowledge about glaucoma and create communication network which would benefit a larger population.

Mass Media

Most studies have documented the effectiveness of mass media and also recommended the same as a successful campaign tool. To the contrary, even though the participants in our study had 100 % access to newspapers and televisions, we did not find mass media as a source of information. Similar report was documented by Tenkir et al.,[20] but unlike our study, their participants had limited access to mass-media. Baker and Murdoch,[26] Nkiru N Kizor-Akaraiwe et al.[27] mentioned a significant increase in awareness of glaucoma but with consistent campaigns with mass-media over years. Parveen Rewri et al.[28] found only a single message related to glaucoma awareness and only three hospital premises had some information on glaucoma during 2016 and 2017. Hence, paucity of glaucoma-related messages and lack of consistent campaigns could be attributed to the ineffectiveness of mass media in health awareness. Also target population in the area should be studied before designing a health message for mass media as stated by Noar[29] in his research on health mass media campaigns.

Social Media and Health Awareness Campaigns

In India, active social media users has increased since 2015.[30] Twitter, Facebook, and WhatsApp dominate the digital platform bridging information and people. Social media has been increasingly utilized in health awareness campaigns. Breast-feeding awareness education through twitter among Saudi Arabia women was influential in that community.[31] In our study 95 % of participants had mobile phones with one or the other social media accounts. But social media was not mentioned as a source of information by any of our participants. A systematic review of seven studies,[32] on the effect of health promotion campaigns done through social media to promote healthy lifestyle habits like tobacco and alcohol was found to be ineffective which supports our finding. Iftikhar[33] has also stated that 78 % of health messages reached the public, but only one fifth of them were influenced by the social media information. There is a pressing need to craft the message with, audience and culture specific content to make it effective. Influential people in social media might contribute to a successful health campaign.[34]

CONCLUSIONS

This study concludes that awareness of glaucoma among rural population is poor. People visiting hospitals had better access to information and opportunistic screening for glaucoma. Close acquaintances and patients with glaucoma

were important sources of information. Mass media and social media are not effective in creating awareness.

Limitations of the Study

Simple survey research could have given an oversimplified outcome. Therefore, future research with a validated questionnaire with large sample size should be done for more generalisability.

Recommendations

Managing glaucoma at the community level requires lot of resources (material and human) and hence, it would be impractical to diagnose and treat glaucoma in outreach camps. Kreuter,[35] in his three-stage model, suggested that the community should be educated to create self-awareness regarding concept of health and to develop personal responsibility of their own health. Therefore, we suggest that, the only way to address the burden of glaucoma, is to propagate awareness and motivate people to utilise eye care centers by changing their behaviour towards their health through effective health education.

Based on our observation, there is an urgent need to change our approach in awareness campaign on glaucoma. We also recommend the following models at various levels as an integrated approach, to increase the health seeking behavior of the people.

Community Based Model

Health care professionals provide better knowledge about glaucoma. Sending the professionals to the community regularly is not feasible. Community representatives could be trained in eye care services as in the LV Prasad Institute Model of Eye Care Services Delivery,[36] where they have the Vision Health Guardians in the bottom tier, who are trained representatives of the community. They are designated with the work of creating community awareness and to screen for eye diseases in the community covering a population of 5000. This community owned health promotion would be a sustainable model in health care delivery.

Designing Health Message

We also recommend that, in a country like India, with a heterogeneous population, there is a need for regional and culture sensitive, context specific approach in planning health communication programs. As recommended in McGuire's communication / persuasion mode,[37] and as stated by Slater,[38] audience segmentation should be considered in designing health message and communication.

Health Account Scheme (HAS) Digital Module

Government of India with the help of ICMR (Department of Health Research), successfully completed research trial Health Account Scheme in three sites (Rural & Urban) Uttar Pradesh and Arunachala Pradesh (Tribal).[39] HAS intervention (community participation to open channels of communication) ensured once a month contact with each one to update health status not only for gathering information but also to take timely actions on identified needs / gaps as well as generated confidence among community. Gaps in health care delivery unknown to local system were detected and sorted using local resources. It will further improve if health diaries are made service linked to ensure compliance.

Once the ICMR Health Account Scheme Project is implemented throughout the country, people can seek help for their eye conditions through their digital health account. The health personal will screen person at the community level and would do the appropriate referrals bringing health to their doorsteps.

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