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Awareness Regarding Screening Programs in General Population to Improve Health Indicators: Genetic Counselors as Facilitators

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Abstract:- Public health screening programs are crucial for early disease detection, but limited awareness hinders their effectiveness in India, regardless of literacy. This study assessed awareness levels for key programs among 294 literate and illiterate individuals via an online survey. Results showed high awareness for antenatal care (96%). Newborn screening (NBS) and thalassemia screening awareness were higher in females, particularly regarding thalassemia's hereditary nature (73% vs 61% and 73% vs 57%). Cervical cancer awareness increased with education (83% for graduates). Interestingly, even those with no education displayed some awareness of breast cancer screening. Prostate cancer awareness was similar across genders, with limited knowledge even among highly educated individuals (66% for Ph.Ds). These findings highlight a critical gap in public health education. Genetic counselors can bridge this gap by implementing targeted campaigns, partnering with schools and communities, and collaborating with healthcare professionals. Empowering individuals with knowledge is essential for improved population health outcomes in India.

Keywords:- *Early Disease Detection, Genetic Counseling, Health Literacy, Population Health Outcomes, Public Health Awareness, Screening Programs in India.*

I. INTRODUCTION

Screening tests are used for identifying asymptomatic individuals, who are at high risk of developing health issues. Screening is a systematic program offered to a specified population of asymptomatic individuals whereby a variety of test methods can be used to make a risk estimate regarding a predisposition to disease, to detect a disease at an early stage, or to make a risk estimate regarding the possibility of transmitting a disease to offspring, for early treatment and disease prevention. Developed countries offer mandatory screening programs to prevent maternal mortality, neonatal/infant deaths, and reduce the burden of cancer. However, most screening programs in India are opportunistic with the Ministry of Health and Family Welfare (MoHFW) promoting them through different programs which vary from state to state. For screening programs to become successful it is essential that people are aware and willing to participate for developing policies to improve population health indicators.

Health Awareness empowers individuals to make the right decisions for reducing diseases and increasing wellness. The uptake of the available screening programs goes hand in hand with the awareness the population has regarding these. According to a 2018 publication the lack of awareness in the Indian population regarding important issues of their health is a major challenge [1]. In the present paper, we have looked at the awareness that individuals from a literate population have regarding four common important health aspects which are listed below:

- Antenatal care (ANC) is implemented with the objective of reducing maternal and neonatal mortality under the National Health Mission by promoting institutional deliveries. The World Health Organisation (WHO) recommends every pregnant woman to have a minimum of four ANC visits, with the first one before 12 weeks [2]. However, only 58.5% of pregnant women in India have had four or more ANC visits [3]. Over the past several decades improvements have been made in India but these are not consistent across the country. Hence, it is important to evaluate awareness in the general population regarding antenatal screening to ensure that 100% of pregnant women receive it.
- Newborn screening (NBS) aims at the earliest possible recognition in babies with disorders to prevent the most serious consequences by timely intervention. Inborn error-born metabolic disorders (IEMs), hemoglobinopathies, congenital birth defects, and various other genetic abnormalities are significant contributors to neonatal mortality, morbidity, and health burden especially in a low-resource country like India. An abnormal screening test needs to be confirmed by further investigations. The number of disorders screened varies from country to country. ICMR and DBT carried out NBS at a community level as a pilot project to plan an effective

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NBS program. However, awareness regarding this in the community has not been established yet.

- Thalassemia is one of the most prevalent Hemoglobinopathy affecting nearly 200 million people globally [4]. Hemoglobinopathies contribute significantly to morbidity and mortality due to the requirement of long-term regular treatment. In India, every year 10,000 children are born with thalassemia which approximately accounts for 10% of the total world incidence of thalassemia [7]. According to a 2022 study, the prevalence of beta-thalassemia varies by region in India with Central India showing 1.4–3.4% beta-thal trait and South India with 8.50–37.90% beta-thal trait [8] this is responsible for economic and emotional distress to the family and is a great drain on the health resources of the country. The WHO has clearly outlined the goals for control of hemoglobinopathies with directives to provide affordable and adequate therapy for those affected and at the same time reduce the number of affected children through strong political, administrative, and financial support. Keeping these guiding principles in mind, the vision of the National Health Mission for India includes carrier screening, genetic counseling, and prenatal diagnosis for hemoglobinopathies [5,6]. Hence, awareness regarding this in our country needs to be assessed for proper implementation of the recommended policies.

- Cancer is a devastating disease and it is well known that early diagnosis enhances survival. Screening programs for cervical, breast, and prostate cancer in various developed countries have reduced their incidence significantly.

✓ Cervical cancer is highly preventable and associated with HPV infection. WHO has recently launched a global strategy to increase preventive, screening, and treatment interventions based on vaccination against HPVs, screening, and treatment of pre- and invasive cervical lesions [9]. The maximum proportion of cervical cancer cases were reported from Asia (58.2%) and it is estimated to affect about 1 in 53 Indian women in their lifetime [10]. For us to achieve the WHO goals, awareness regarding screening needs to be assessed and appropriate measures taken to prevent cervical cancer.

✓ Breast cancer is the most prevalent cancer and the foremost cause of cancer death among women across the globe [11,12]. It's prevalence in India, is 25.8 cases per 100,000 people [13]. Screening for breast cancer by mammography is an effective measure to detect early-stage disease and improve the survival rate of cancer patients. [14, 15]. However, India does not have a mandatory breast cancer screening program and awareness regarding this needs to be established.

✓ Prostate cancer is the only male cancer that has a screening program in all developed countries. The incidence of prostate cancer in India ranges from 5.0 to 9.1 per 100,000 individuals/year [16]. Prostate-specific antigen (PSA) testing and ultrasound evaluation of prostate volume are the common screening methods for the identification of males at a high risk of developing prostate cancer. We believe that the awareness regarding this is not very high amongst developing countries, especially with a low socioeconomic background like India.

Since the results of screening tests indicate a high or low probability of getting the disease, they are extremely important for early diagnosis and prevention of several diseases/ disorders. Screening can be carried out on individuals of all ages and in this study, we conducted an online survey using Google Forms to assess awareness regarding screening tests. The survey was conducted in English language which consisted of 12 questions, 3 of them were about demographic details while the others were regarding awareness about antenatal, newborn, thalassemia, and cancer screening.

II. MATERIALS AND METHODS

➢ *Survey Design*

An online survey was designed through Google Forms in the English language. The questionnaire was of mixed type which consisted of Multiple-Choice Questions, Checkboxes, and Yes/no questions. The survey had 12 questions divided into 2 sections: 3 of them being the demographic questions and the others related to the different screening programs. In terms of demographic data, there were questions on gender, age, and educational background. The questions were related to assessing public awareness regarding screening tests, carried out during pregnancy, at birth, for thalassemia and cancer. There was one question (No.3) where multiple options could be selected and this even included the option "None" was also provided at the end. The survey started with an introductory paragraph which provided information on the purpose and scope of the research. The survey was online from November 2023 to January 2024 and was publicized on various social media platforms which included LinkedIn, Facebook, Twitter, and WhatsApp. (survey form attached)

III. RESULTS

The total number of participants who took the survey was 295 out of which 195 were women and 99 were men. They belonged to the age group 18 to 65 years. Most of the individuals were educated with only 9 of them having no formal education (figure 1b). One participant was excluded as she only answered the demographic questions and did not complete the total survey. Therefore 294 responses were analysed (figure 1 a).

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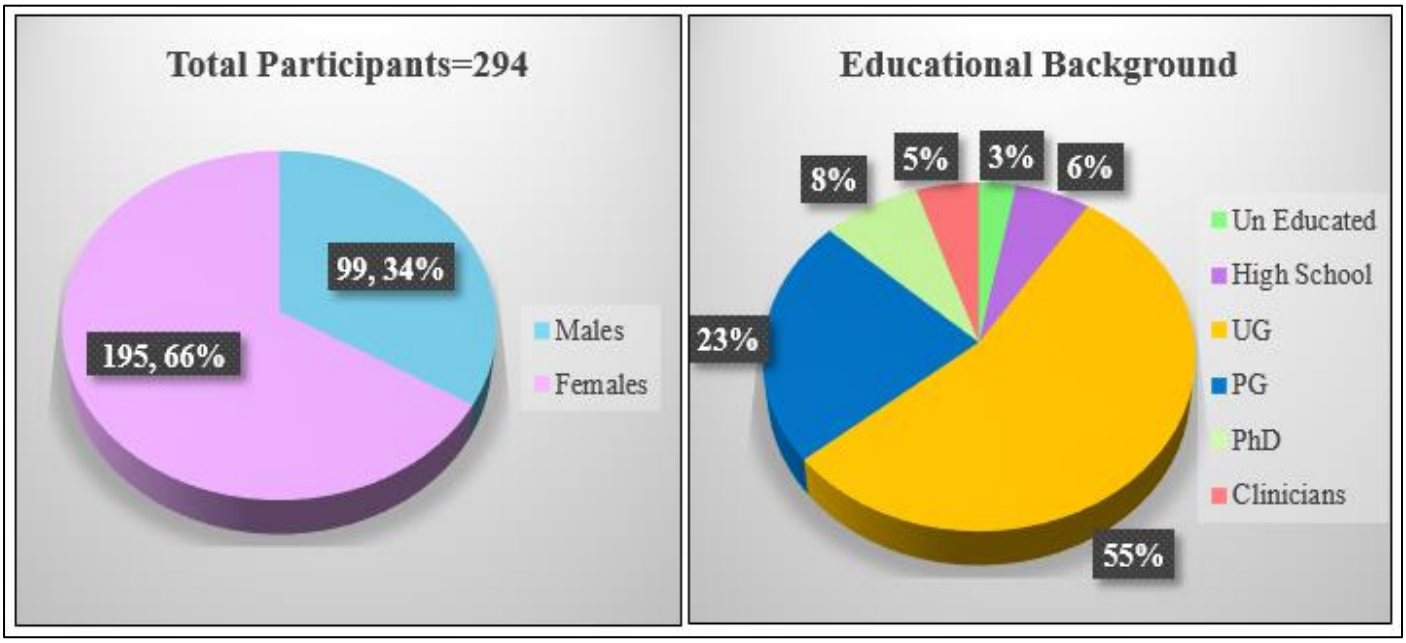

Fig 1a, figure 1b

Table 1 Number of Participants along with their Ages and Educational Background.

Ages	Un Educated	High School	UG	PG	PhD	Clinicians
18- 24 (N= 146)	-	06 (4.10%)	112 (77%)	21 (14.3%)	04 (3%)	03 (2%)
25- 40 (N=95)	04 (4.2%)	02 (2.1%)	29 (31%)	36 (38%)	14 (15%)	10 (11%)
41- 60 (N= 41)	05 (12.1%)	09 (22%)	13 (32%)	07 (17%)	05 (12.1%)	02 (05%)
>60 (N= 12)	-	01 (8.3%)	07 (58.3%)	04 (33.3%)	-	-

Maximum awareness was for the question which was about tests required in pregnancy with very little difference in men (94%) and women (96.40%), however, the awareness increased along with the level of education as shown in Figure 2 below.

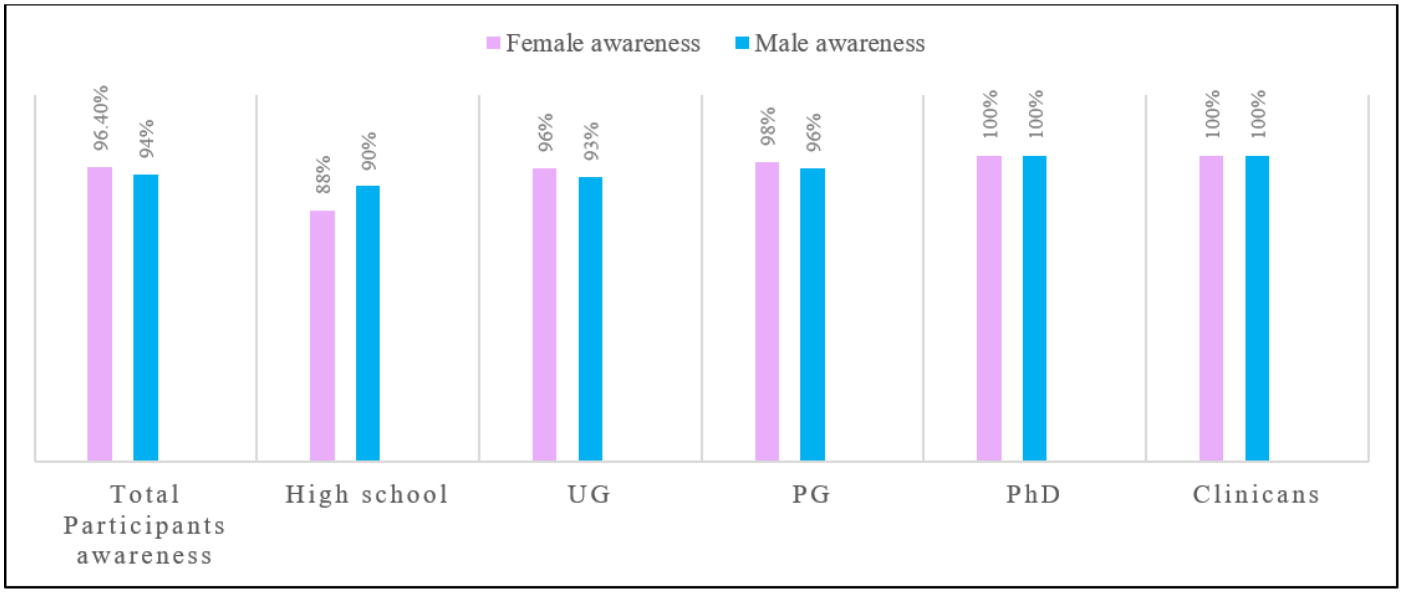

Fig 2 Are you aware that Pregnant Women Require Various Tests?

Although the majority of individuals were aware of the antenatal tests required, but less than 41% were aware of all four screening tests. Surprisingly only 33% of clinicians were aware of all the screening tests as given below in Figure 3.

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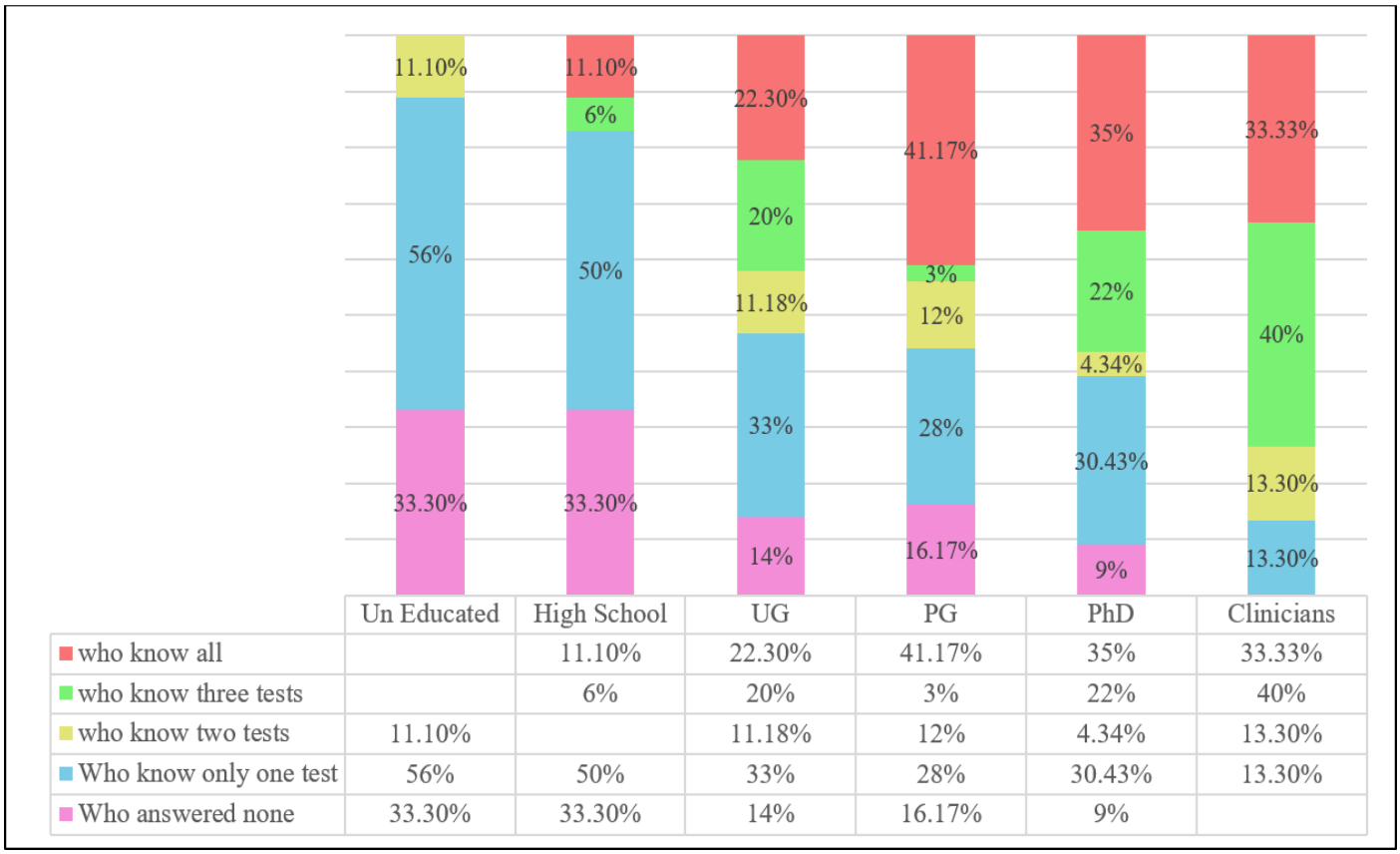

	Un Educated	High School	UG	PG	PhD	Clinicians
who know all		11.10%	22.30%	41.17%	35%	33.33%
who know three tests		6%	20%	3%	22%	40%
who know two tests	11.10%		11.18%	12%	4.34%	13.30%
Who know only one test	56%	50%	33%	28%	30.43%	13.30%
Who answered none	33.30%	33.30%	14%	16.17%	9%	

Fig 3 Which One of these Tests do you Know?

(A) NT scan (identifies nasal bone, detects neural tube defects between 11-13 weeks), (B) NIPT (screening for chromosomal anomalies in the baby from 12th week), (C) TIFFA scan (examines all major fetal organs 18- 22 weeks), (D) Biochemical Tests (Double marker, Triple marker, Quadruple marker).

The question dealing with newborn screening had a much lower awareness being only 61% in males and 72.8% in females. Individuals with high school education had very low awareness which increased with education. In all categories including those of clinicians' females were more aware than males about NBS. Surprisingly only 67% of male clinicians were aware of NBS as shown below in Figure 4.

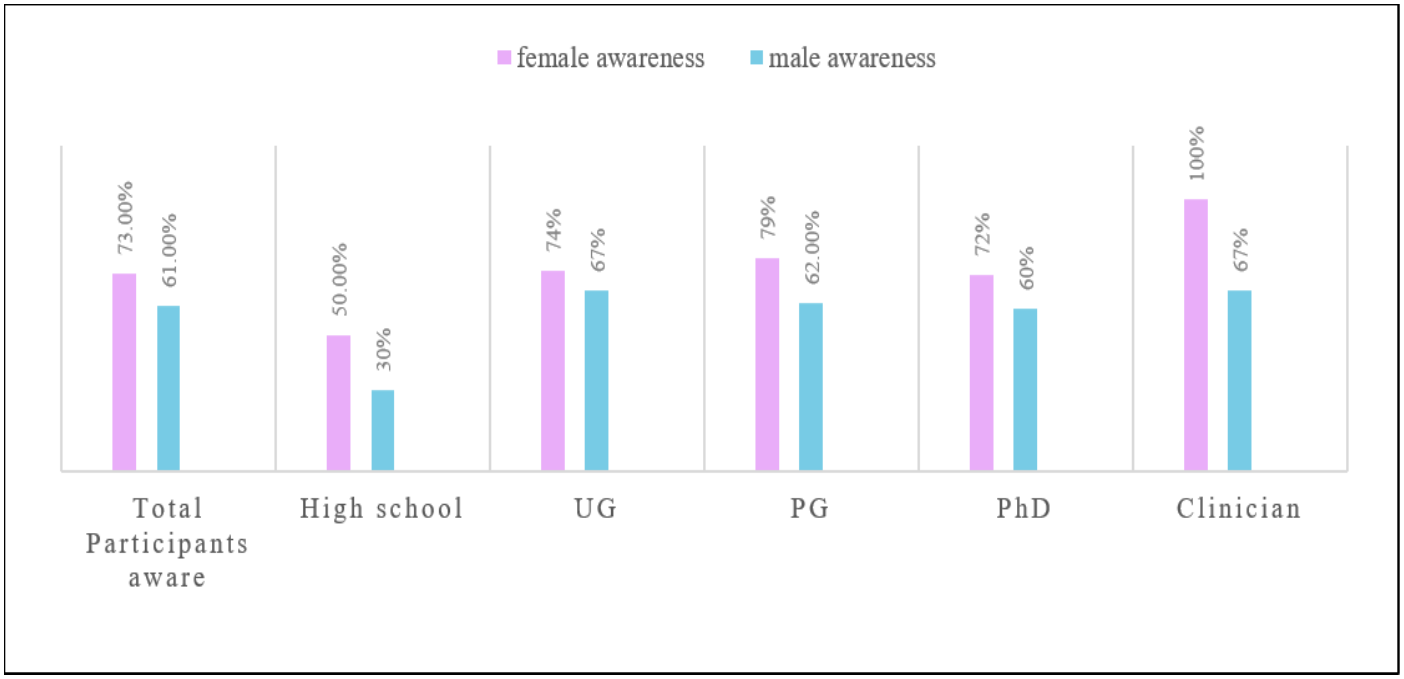

Fig 4 Do you know Newborn Screening (NBS) is done any Time after the Third Day of Birth and it Checks for the Risk of Several Diseases?

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The level of awareness regarding thalassemia was significantly different between men (58%) and women (73.3%) with women being more aware in High school, UG and PG groups. Not all individuals with a PhD were about it. None of the uneducated individuals were aware as shown below in Figure 5.

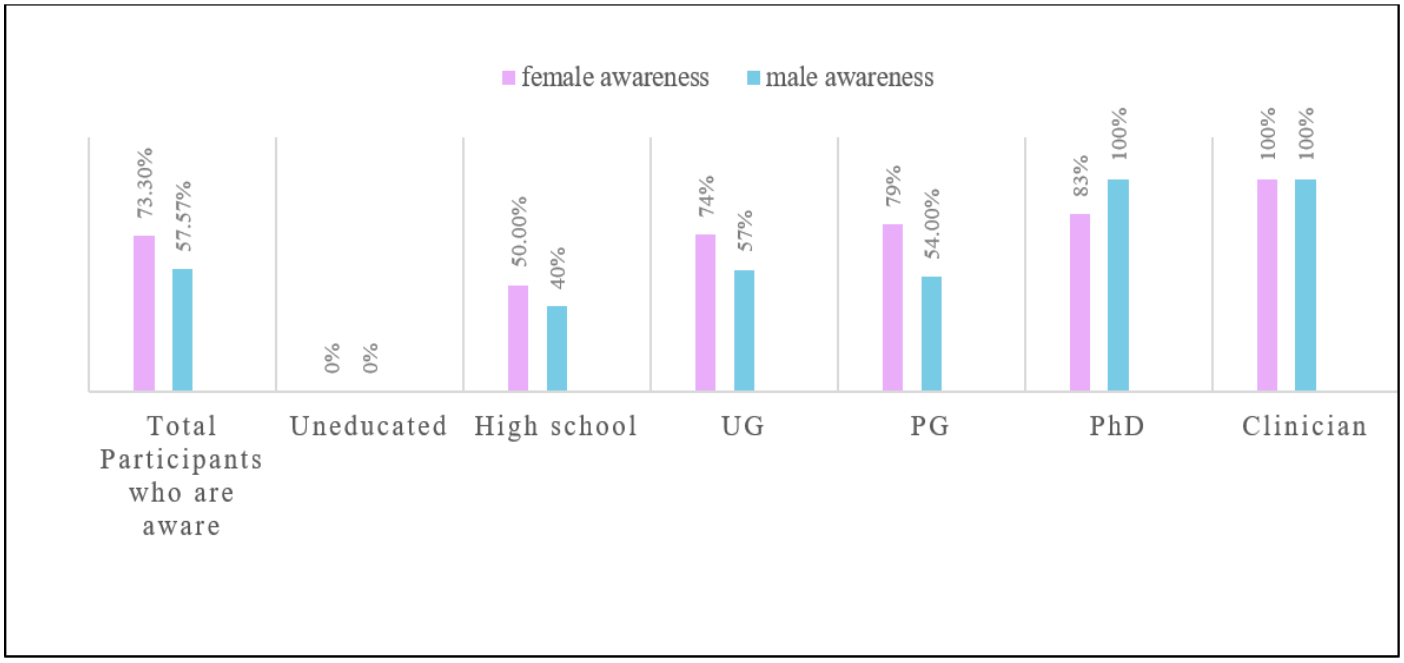

Fig 5 Did you Know that the Thalassemia Carriers do not Show the Symptoms but can Pass on to their Children?

Men (59%) were less aware when compared to women (76%) about the pap test. There was about 83% awareness in the women with UG and PhD backgrounds. Males did not show much awareness who had less education qualification. However, the awareness was greater in males with higher education as shown in Figure 6 below.

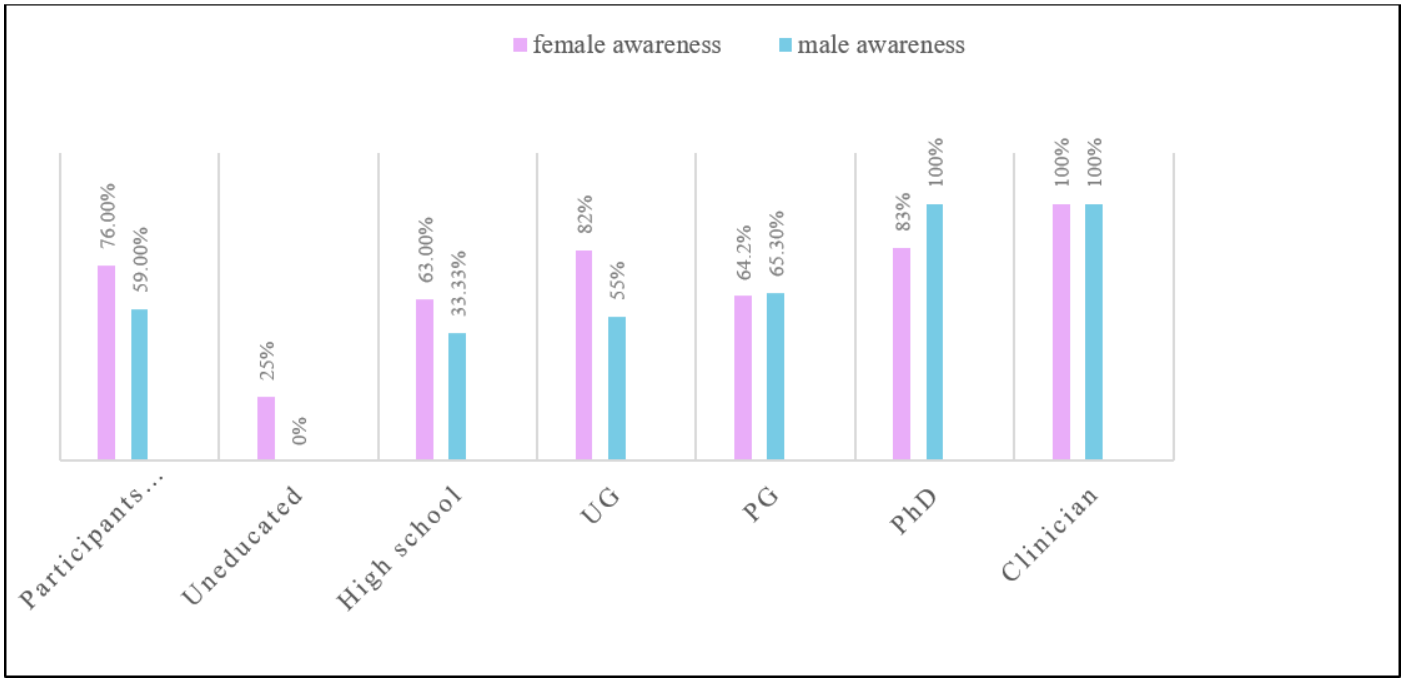

Fig 6 Are you aware that pap Test is a Routine Screening Procedure for Cervical Cancer?

A difference of awareness regarding mammogram screening for breast cancer was seen between males (78%) and females (85.12%). Even uneducated individuals (N= 09) were aware about it. Males were more aware in two categories- Postgraduates and Clinicians as shown in Figure 7 below.

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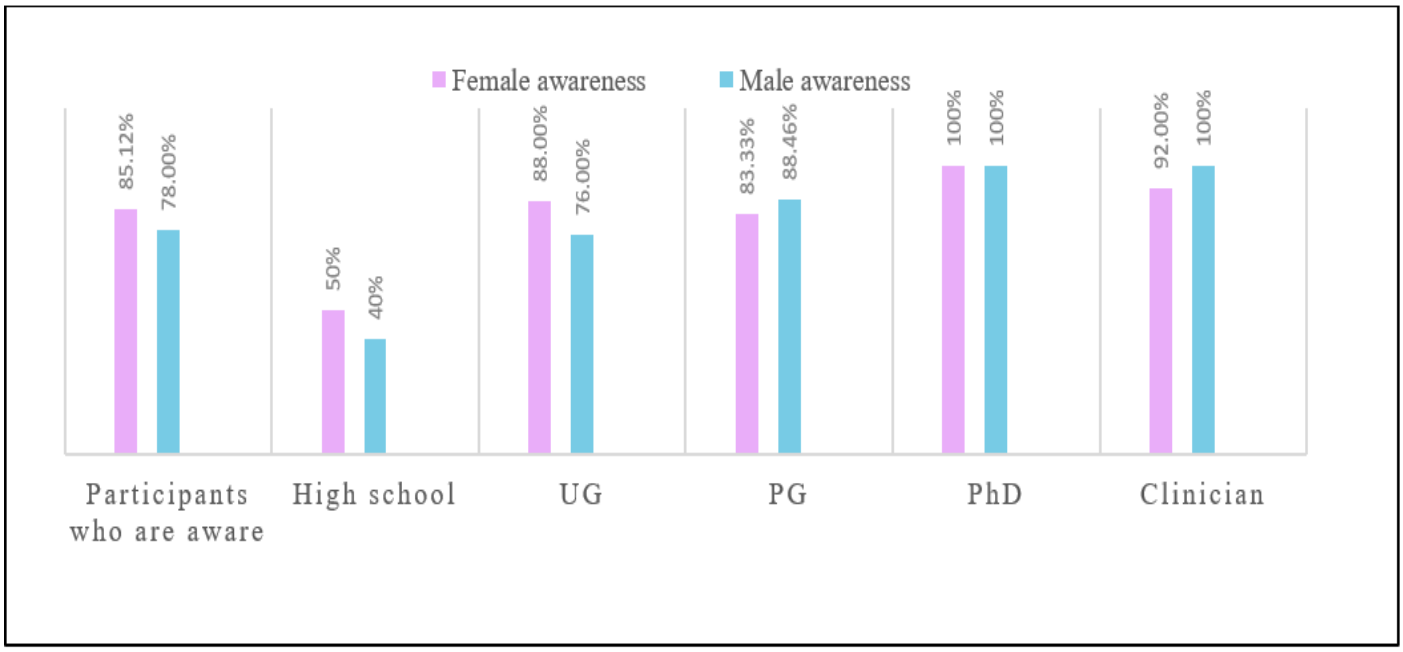

Fig 7 Have you Heard that Screening of Breast Cancer is done by a type of X-ray, called Mammogram and Ovarian Cancer by Ultrasound?

Awareness regarding PSA test for Prostate cancer was extremely low in both males (54%) and females (54.8%). Awareness increased with higher education but was still around 66% in individuals with a PhD as shown in Figure 8 below.

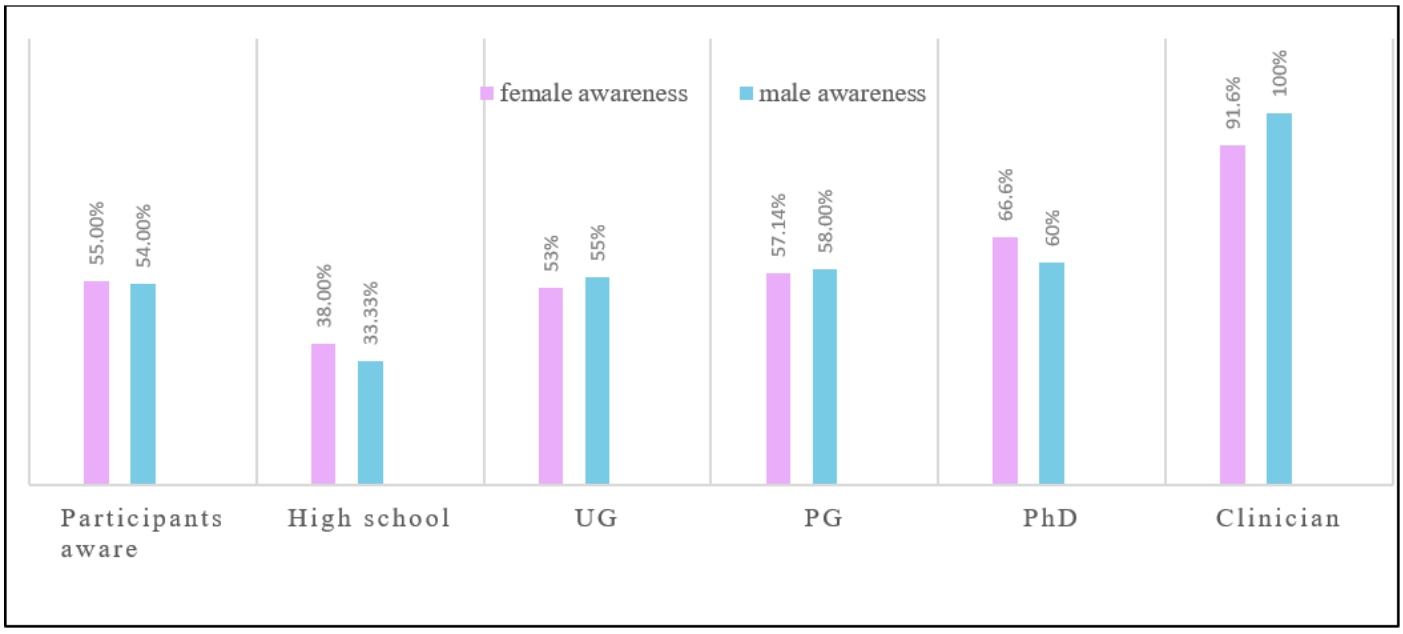

Fig 8 Have you Heard the Diagnosis of Prostate Cancer is done by PSA Test?

IV. DISCUSSION

Awareness regarding various health tests results in better health-seeking behavior and is a pre-requisite to well-being, as well as, early detection/prevention of various disorders and cancer. This paper deals with awareness in the general population regarding screening tests available in India for different stages of life. The results will be helpful in the successful implementation of health programs and the development of health policies. The limitation of the present study is that this study relied on an online survey, potentially excluding individuals with limited internet access or those unfamiliar with English, this may skew the results towards a younger, more tech-savvy population, potentially misrepresenting awareness levels in the general public. The sample size (294) is relatively small and geographically concentrated (survey promoted on social media platforms). This limits the generalizability of the findings to the entire Indian population and this study relies on self-reported awareness, which can be prone to bias. Participants may overestimate their knowledge or be influenced by social desirability. Of the total 294 participants, there were more females (66%) than males (34%) with a ratio of 2:1. All the

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participants were literate with only 9 with no formal education, the maximum number of participants were in the UG category (55%) and 77% of these were in the age group 18-24 years indicating that young people are more likely to participate in online surveys. The older individuals who took the survey were mostly UG followed by PG and High school as shown in Table (1). The results in the present study showed that 96% of the general population was aware that screening tests are required during pregnancy. This was independent of their gender, age, and educational status. (Figure 2). This is similar to a previous study by Bashir et.al (2023) which showed that 96% of women had knowledge about Antenatal care [17]. A similar study in a rural population reported awareness in 57.36% women about the tests during antenatal period [18]. However, both these studies were carried out in pregnant women. Our survey included men since they play a crucial role in supporting women financially specially in a country like India where women are dependent on male partners for their antenatal care. We believe that awareness regarding antenatal care in men is extremely important for them to support their female family members in obtaining appropriate care during pregnancy. It was concerning that 33% of uneducated and high school-educated individuals were not aware of any specific individual tests required during pregnancy, while 56% knew that they required an ultrasound scan but were not sure about the timing and relevance of the NT scan and TIFFA scan. Surprisingly, 41% of individuals with a PG education were aware of all tests listed in the survey, which was more than the percentage awareness seen in PhDs and Clinicians (Figure 4). From these observations, it can be recommended that it is important to create awareness regarding antenatal screening in both girls and boys from a young age preferably as a course in the tenth grade, as well as a training module for clinicians upgrading their awareness with current screening tests available. Genetic counselors can provide in-depth explanations, discuss the chance of a positive result and what it might mean, and address emotional concerns that can arise during pregnancy. This personalized approach can empower couples to make informed decisions about their pregnancy and healthcare options.

In our current study, the overall awareness of NBS was relatively lower than that observed about antenatal care. However, it was higher in females (73%) in comparison to males (61%) in all educational categories except for clinicians (Figure 3). A similar survey conducted in Nepal in parents of young children by Khan et.al (2024) showed that 67% reported a moderate understanding of NBS [19]. According to a survey based on awareness of NBS among parents and community healthcare workers in the Udupi district of South India the initial awareness level was in 30% of the participants which increased up to 98% after awareness-creation activities were carried out, [20] suggesting that awareness programs in young married couples and those coming for antenatal care should be encouraged. Genetic counselors can provide crucial post-test counseling, explaining the nuances of NBS results, potential treatment options, and connecting families with relevant specialists if needed. This personalized guidance can alleviate anxiety, address misconceptions, and empower parents to make informed decisions about their child's healthcare.

Hemoglobinopathies represent a significant public health concern on a global scale. These are inherited disorders characterized by abnormalities in the production or structure of hemoglobin, the vital protein within red blood cells responsible for oxygen transport. According to the WHO, approximately 5% of the world's population carries a hemoglobinopathy trait. Furthermore, the prevalence of anaemia, a condition often associated with hemoglobinopathies, is alarmingly high, particularly in low- and middle-income countries, including India. A study conducted by Biswas et.al (2020) on the quality of life of the parents of thalassaemic children showed that the correct knowledge of the cause of thalassemia in the parents (mothers- 75.9%, fathers- 24.1%) was 48.2% [21]. Another study which was conducted in Rajasthan by Kumar et.al (2020) showed that 41.4% of males and 44.8% of females were aware about genetic transmission of thalassemia. The level of awareness increased to 78% when there was an affected family member [22]. Our current study emphasized that the level of awareness among women (73%) regarding the hereditary nature of thalassemia was higher than that of men (57%) (Figure 5). Awareness regarding carrier testing and HPLC screening should be best provided to adolescents and at the time of marriage to both men and women as is the policy in countries like Iran, Cyprus, etc (Ministry of Health and Medical Education of Iran. National carrier screening program for thalassemia and hemoglobinopathies in Iran. (2019, August 13). [health.gov.ir], https://www.tandfonline.com/doi/full/10.1080/03630269.2020.1719606). While public awareness initiatives raise awareness of hemoglobinopathies, integrating genetic counseling services is crucial. Genetic counselors offer clear breakdowns of carrier screening and prenatal diagnosis, outlining risks, benefits, and inheritance patterns. This empowers couples to navigate complex medical decisions and make informed reproductive choices, ultimately promoting family health.

The treatment of cancer is long, which is physically, emotionally and economically draining both for the patient and family. Hence, early identification and prevention is the best option, Cervical and breast cancer affect women in the age group of 40-60 years globally. Both these have well-implemented screening programs in developed countries. Pap smear screening is the most prevalent test for cervical cancer even today, but only 83% of women who are graduates or above were aware of this according to our survey (Figure 6). An earlier paper from Urban South Indian women showed that 82% were not aware of pap smear screening. This may be because most of them had only a school education [23]. Results from our study showed that 48% of individuals with school education have knowledge about pap smears and this increased with education (Figure 6). While Pap smears are the mainstay of cervical cancer screening, awareness remains a hurdle, particularly among those with limited education. Genetic counseling can bridge this gap. These specialists can explain the rationale behind Pap smears, who should get them, and how they fit into a comprehensive cervical cancer

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prevention strategy. This empowers women to take control of their health and complements public awareness initiatives.

A study from Mumbai found that regular clinical breast exams by primary health workers every two years led to early detection of breast cancer and a nearly 30% drop in deaths for women over 50 years, though the overall mortality reduction wasn't statistically significant [25]**.** Limited resources force many countries to adopt diverse minimum ages for breast and cervical cancer screenings. Vietnam, for instance, recommends starting breast cancer screening at 20, while India waits until 50 years. This disparity extends to cervical cancer screening also, with China starting at 18 years compared to India and Indonesia which start screening at 30 years. Despite established guidelines, screening uptake remains low across developing countries [26]**.** Southern states of India like Andhra Pradesh, Tamil Nadu, Kerala, and Telangana, along with Maharashtra in the west and some northeastern states like Mizoram and Manipur, demonstrate significantly higher screening rates for breast and cervical cancer compared to other regions in India [27]. This study revealed that only 34% of participants were aware of cancer screening programs for early detection. Among those aware, media was the primary source of information (71%), followed by friends/relatives (47%). It is extremely worrying, that healthcare professionals like nurses and doctors were a low source of information (31%) even traditional channels like schools (17%) and religious institutions (14%) had limited reach [28]. Meanwhile, in our study, an interesting trend was observed regarding mammogram screening for breast cancer. While females had a slightly higher awareness (85.12%) compared to males (78%), even the nine uneducated participants were aware of it. Surprisingly, males showed higher awareness in two specific categories: postgraduates and clinicians (Figure 7).

The only male cancer which has a screening program is prostate cancer and this involves PSA assessment and ultrasound. A study conducted by Kayum et al (2021) which assessed the knowledge of men about prostate cancer shows that 47.48% of them were aware of prostate cancer screening [24]. Whereas our study revealed a similar result with 54% awareness in both men and women. The awareness reached only 66% even among highly educated individuals with PhDs (figure 8). Surprisingly more awareness was in women (55%) even for this male cancer. To raise awareness among individuals, especially in men, developing informative campaigns specifically focused on men's health, educate doctors and nurses to proactively discuss prostate cancer screening with male patients during regular checkups, organizing educational workshops and seminars in communities to raise awareness about prostate cancer and the importance of early detection and by integrating age-appropriate information about men's health and prostate cancer into school curriculums. This can empower future generations to make informed decisions about their health. By implementing these strategies, we can bridge the knowledge gap and encourage men to have open conversations with their doctors about prostate cancer screening. Early detection is crucial for successful treatment and better patient outcomes. While some general awareness exists in our literate population about screening tests, from our survey we were not able to assess if it is translating into participation in screening programs. This suggests a need for improved public health initiatives to increase the involvement of genetic counselors as healthcare workers in educating communities, partnering with schools, community centers, and religious institutions for wider outreach, to promote early detection by emphasizing the importance of screening as per guidelines. Genetic Counseling will lead to filling the critical gap between awareness and action.

V. CONCLUSION

This study reveals a public health awareness gap in India's screening programs. Despite literacy, awareness is limited regarding screening programs and hence, this knowledge doesn't translate to participation. To overcome this gap, Genetic counselors can be involved in providing targeted education to promote public health initiatives in antenatal, newborn, thalassemia, breast, and prostate cancer screening. This strategy can empower individuals to take informed healthcare decisions, and can serve as a model for other low-resource countries.

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