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Familiarity, Knowledge, Attitude and Willingness towards Genetic Counselling among the South Indian Population

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ABSTRACT

The effect of any kind of genetic disorder is almost irreversible in life, so it is very important to understand these disorders and the modern, effective preventive approaches available to reduce the familial and societal burden. This study aims to measure the awareness of Genetic Counselling (GC) and investigate personal factors like knowledge, attitude, and willingness towards the purpose of genetic counselling among the South Indian population. Individuals from the state of Tamil Nadu, Karnataka, Andhra Pradesh, Telangana, Kerala, and Pondicherry participated in the study. Knowledge score was generated for everyone, ranging from 19 to 42, with which varied results were generated compared to other variables. Four hundred and sixty-seven individuals completed the survey. About fifty-nine percent of the respondents reported familiarity with GC and the main source of knowledge was through media. Positive attitude and willingness towards GC were reported in the population. Knowledge of GC showed a different trend when compared to other studies of similar objectives. The need for more qualified professionals in the field and the inclusion of genetic counselling and testing as a primary preventive measure in government health care sectors will help reduce the burden of genetic diseases in families and society.

Key words:
genetic counselling; awareness; knowledge score; genetic disorders.

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INTRODUCTION

Genetic Counselling (GC) is the communication process that aims to help individuals, couples, and families understand and adapt to medical, psychological, familial, and reproductive implications of genetic contributions to diseases[1]. The concept of genetic counselling was coined well before molecular and cytogenetic testing when only family information was available as the source to assess the occurrence and recurrence of a particular genetic condition. Tremendous improvement is seen in biomedical sciences and the diagnostic health care sector had made many pre-tests and genetic tests available to help with genetic counselling and to make informed choices. Genetic conditions and congenital disorders affect 7.9 million children across the world. Low- and Middle-income countries (LMIC) had shown a decrease in morbidity and mortality caused by communicable diseases, nutritional deficiencies, maternal and neonatal complications with improved medical care for many years[2]. 94% of children born with congenital anomalies belong to LMIC[3]. Non-communicable diseases with congenital anomalies and genetic conditions affecting children under age 5 are the fifth leading cause of mortality and morbidity[4]. It is also estimated that 70% of deaths related to non-communicable diseases occur in LMIC[5]. India being one such country, adapting modern prevention strategies like genetic counselling and testing to reduce the incidence of genetic conditions becomes indispensable for which awareness of such preventive strategies is very important. Genetic counselling had proved to be an effective preventive strategy to reduce the incidence of genetic disorders in western countries and had been practised since the 1960s. The children born with major genetic conditions suffer severe multiple ailments and face complete rejection and unacceptance from society.

India as a country had seen quite a significant breakthrough in medical diagnostics with the advent of modern technological advances like chromosomal microarray analysis, whole-exome sequencing, genetic markers testing and mutation screening which is often paired with genetic counselling. These technological advances in the health care sector are not available to everyone in need even when their risk factors are predominant. Risk factors contributing to a genetic condition were taken into consideration only after diagnosis because the state does not include any prevention strategies for genetic conditions in public health care protocols in South India. Very few private sectors educate their patients regarding such conditions, therefore measuring the awareness of genetic counselling and its purpose will help strategize the adoption of preventive measures which in turn will reduce the burden of irreversible genetic conditions in families as well as in society.

South India is a region encompassing the states- Andhra Pradesh, Karnataka, Kerala, Tamil Nadu, Telangana, and the union territories of Lakshadweep and Puducherry. According to the 2011 census of India, the estimated population of South India is 252 million, around 20% of the total population[9]. The majority of the people in South India speak one of the four major languages: Telugu, Tamil, Kannada, and Malayalam. Kerala and Tamil Nadu achieved the goals related to the improvement of maternal health and reduction of infant mortality and child mortality by 2009[10]. There are very less studies that measured the public awareness of genetic counselling [6,7,8]. This study aims to measure the awareness of genetic counselling and investigate personal factors like knowledge, attitude, and willingness

towards the purpose of genetic counselling among the South Indian population.

METHODS

A cross-sectional, quantitative survey based on "google forms" was distributed through WhatsApp and e-mail among the South Indian population. The option of google form was undertaken since the pandemic situation did not allow physical distribution of questionnaires or face to face interviews. Institutional Ethical Committee approval for the study was obtained from the Sarah Tucker College-Institutional Ethical Committee (STC-IEC) with the standard operating procedure as directed by ICMR (Indian Council of Medical Research), Certificate -No: IEC2021-003-Z**.** The questionnaire starts with an information sheet that provided details explaining the objective of the study along with the contact details of the principal investigator to clarify any queries regarding the study. It assured the participants that their information would be used only for research purposes. There is no right and wrong response. The participants were assured of confidentiality and were also assured that their responses will not be published pertaining to an individual's identity. Consent to take part in the study was asked as a question for which the participant must answer "Yes" or "No" before proceeding with survey questions. A total number of 467 individuals from the states of Tamil Nadu, Karnataka, Andhra Pradesh, Telangana, Kerala, and Pondicherry participated in the study. Sample size calculations were done with a 95% confidence level and a 5% margin of error to produce statistically significant results which needed 385 samples. There were no prerequisites involved in participating in the study. All participants, male and female of age 18 yrs. and above belonging to Tamil Nadu, Karnataka, Andhra Pradesh, Telangana, Kerala, and Pondicherry were included in the study.

A pretested questionnaire adopted from studies carried out in a rural population of USA[8], the Hutterite population of Canada[9] and a hospital population of Ethiopia[10] was used in this study. The survey statements used to measure knowledge and attitude were assessed for accuracy independently by seven genetic counsellors and were evaluated for reading level using The Flesch Kincaid Grade Level Scale ranging in grade levels 6.7-11[8.]

The survey was administered in English, and it consist of three sections. The first section collected demographic information including gender, age, religion, place of residence, ethnicity, marital status, educational level, and whether the individual has children or not. Demographic response options were modified according to the population. The second section assessed familiarity and the source of familiarity. The third section consists of a brief description of GC as described in previous studies adopted from the website of the National Society of Genetic counsellors mentioned under the topic of Genetic counselling as a profession. According to the definition "*Genetic counselling is the process of providing information and support to families who may be at risk for a variety of genetic and inherited conditions. Genetic counsellors identify families at risk, investigate the problem present in the family, interpret information about the condition, analyse inheritance patterns and risk of recurrence, and review available options with the family*"[13]. The participant's knowledge of the genetic counselling section consists of 11 questions and was administered to all participants (regardless of whether they are familiar or not familiar). Participants were asked to state their responses on a Likert scale from 1 to 4 (1=disagree, 2=somewhat disagree, 3=somewhat agree, 4=agree). Following the 11 questions, the third section also consists of 3 questions that assessed the

attitude and willingness of an individual towards GC. The final question assessing the willingness of an individual to receive genetic counselling services in the future was given as an open-ended question in previous studies, but this study had assessed the willingness on the same Likert scale of 1 to 4 as all other statements. Out of the first 11 statements that assessed the knowledge in Section 3, 7 statements were inaccurate, and 4 statements were accurate as indicated in Table 5. Disagreement to an inaccurate statement and agreement to an accurate statement was considered as the correct perception of purpose. Three questions on attitude and willingness were also accurate statements and followed the same trend as the previous section.

In addition to applying descriptive statistics to summarize the data, a knowledge score was created for each participant. When a respondent strongly agreed with an inaccurate statement the score is 1, similarly, when a respondent had strongly agreed with an accurate statement, the score is 4 and vice versa. So, the minimum score a participant can get for each statement is 1 and the maximum score is 4. For all the 11 questions assessing the knowledge, the average score can range from 11 to 44. The mean response for each statement was also calculated out of 4. For analysis, a mean response of <2.5 indicates disagreement with the statement while >2.5 indicates agreement with the statement. T-test was carried out to analyse the comparative status between the studies with the same objective from different regions of the world. One way ANOVA (Analysis of Variance) was carried out with knowledge score as the fixed variable to analyse the different status of familiarity. Familiarity and socio-demographic factors were other variables that were cross-compared and analysed to produce varied results.

RESULTS

Sample demographics

Table 1 contains the summary of respondent demographics. Out of 467 individuals, 289 were males (61.88%) and 174 were females (37.26%) and the vast majority belong to Tamil Nādu (77.94%) with Tamil as their mother tongue. The respondents ranged in age from 18-50 and above. Respondents of age 21-35 were the highest, about 47.75% followed by respondents of age 36-50 about 29.12%. At the time of the survey, 63.17% of respondents completed post-graduate degrees and above and 34.9% were undergraduates. Married and unmarried respondents formed 63.38% and 34.90% respectively. Among the respondents, 62.24% follow Hinduism, 32.55% follow Christianity, 2.36% follow Islam and 3.85% had some other belief systems. Almost 49.46% of the respondents have children and the other 50.54% do not have children.

Table 1. Summary of the Respondent's Demographics

No	Particulars	Specific details	Number	%
1	Gender	Male	289	61.88
		Female	174	37.26
		Prefer Not to Say	4	0.86
2	Age	18 to 20	33	7.07
		21 to 35	223	47.75
		36 to 50	136	29.12
		51 and above	75	16.06

No	Particulars	Specific details	Number	%
3	Education Level	School Level	3	0.64
		Undergraduate	163	34.90
		Post-Graduation and Above	295	63.17
		Others	6	1.28
4	Relationship Status	Un-married	163	34.90
		Married	296	63.38
		Divorced	3	0.64
		Widowed	5	1.07
5	Religion	Christianity	152	32.55
		Hinduism	286	61.24
		Islam	11	2.36
		Others	18	3.85
6	Mother Tongue	Tamil	364	77.94
		Malayalam	32	6.85
		Telugu	37	7.92
		Kannada	10	2.14
		Hindi	10	2.14
		Others	14	3.00
7	Have Children	Yes	231	49.46
		No	236	50.54
8	State of Residence	Tamil Nadu	369	79.01
		Andhra Pradesh	5	1.07
		Karnataka	58	12.42
		Kerala	22	4.71
		Telangana	10	2.14
		Puducherry	3	0.64

Respondents' self-reported Familiarity with genetic counselling

Among the respondents, 59.10% had reported "Yes" for familiarity with GC and 40.9% had reported "No" for familiarity with GC, out of which 30.41% had reported that they have not heard of the term before. About 10% of the respondents had stated that they have heard of the term, but they were not familiar with Genetic counselling. Media was the main source of information on GC followed by schools and colleges and then through health care centres as shown in Table 2. Out of 467 respondents, 5 had received services by themselves which was about 1.07%. Among the respondents, 64.36% of males and 67.25% of females were familiar with GC. About 56% of people in the age group 21-35 were familiar and 62.50% of people in the age group 35-50 were familiar. Postgraduates and undergraduates of about 58.64% were familiar. Both single and married people had reported similar familiarity of about 60%. People with children had similar familiarity- 59.92% when compared to people without children- 58.58%.

Table 2. Source of knowledge on GC**.**

Source of Knowledge	Number	%
Family / Friends	82	17.55
Media	131	28.05
Not Heard	142	30.40
School/ College	110	23.55
Hospitals/ Health Centres	49	5.03
I have received	5	1.07

More than one option had been selected by some respondents

Table 3. Average knowledge score of different status of familiarity and demographic categories

Category	Average
Yes - familiar	*29.75*
No-Not familiar	*30.67*
Male	30.14533
Female	30.14943
School Level	25.33
Undergraduate	29.77
Post-Graduation and Above	30.406
Others	28.66
Single	29.938
Married	30.1655
Widowed and divorced	30.23
Christianity	29.86
Hinduism	30.09
Islam	30
Others	33.11
Have Children	30.19
No Children	30.05

Table 4 One way ANOVA- different status of familiarity in comparison with knowledge score.

Included groups	p-Value	Excluded group
Very Familiar Not Familiar Somewhat Familiar Familiar	0.05842	None

Included groups	p-Value	Excluded group
Familiar Not Familiar	0.02825	Very Familiar
Somewhat Familiar Very Familiar		
Somewhat Familiar Familiar	0.45864	Not Familiar
Very Familiar Not Familiar	0.11953	Somewhat familiar
Familiar Very Familiar		
Not Familiar Somewhat Familiar	0.06151	Familiar

Table 5. One on one comparison between knowledge scores of different status of familiarity

Groups	Not Familiar	Somewhat Familiar	Familiar	very Familiar
Not Familiar	-	0.01999	0.0397	0.9990
Somewhat Familiar	0.01999	-	0.7530	0.2554
Familiar	0.0397	0.7530	-	0.2531
Very Familiar	0.9990	0.2554	0.2531	-

Significance level- $\alpha=0.05$, $p<0.05$ indicates there were no significant differences between the mean values of compared categories. $p>0.05$ indicates there were significant differences between the means of compared categories.

Table 6. Attitude and willingness of the respondents.

Attitude	Mean
I would trust the information provided by a genetic counsellor.	3.257
Genetic counselling is in line with my values.	3.128
Willingness	Mean
I am willing to avail genetic counselling as a service from qualified genetic counsellors if the need arises.	3.287

Average mean >2.5 indicates a positive trend and <2.5 indicates a negative trend towards the statements.

Table 7: Knowledge and attitude towards genetic counselling of present study in comparison with previous studies.

Statements	South Tamil Nadu- Mean	Standard deviation	Ethiopia- (Jacob et al.,2020) Mean	Standard deviation	p-value	USA- (Reisgraf et al.,2015) Mean	SD	p-value	Canada- (Gemmell et al.,2017) Mean	Standard deviation	p-value
The goal of genetic counselling is to keep genetic problems out of society. *Inaccurate*	1.931	0.96484	3.36	1.16	<.001	2.29	1.05	0.002	2.99	1.14	<.001
Genetic counselling is confidential. Accurate	3.302	0.83695	2.85	1.4	0.002	3.64	0.69	<.001	3.48	0.9	0.06
Genetic counselling gives people emotional support-Accurate	3.216	0.80657	3.77	0.75	<.001	3.25	0.84	0.626	3.38	0.82	0.059
Genetic counselling is a service mainly for pregnant women- Inaccurate	2.642	1.06574	2.18	1.37	0.002	1.73	0.86	<.001	1.2	0.42	<.001
Genetic counsellors require people to have genetic tests- Inaccurate	2.111	0.9496	2.14	1.35	0.838	2.57	1.05	<.001	2.93	1.21	<.001
Genetic counselling is only useful to a small group of people with rare diseases. Inaccurate	2.745	1.05882	1.77	1.22	<.001	1.72	0.86	<.001	1.53	0.88	<.001
Genetic counselling may be helpful for someone with cancer in their family. Accurate	2.998	1.00107	2.72	1.37	0.056	3.46	0.69	<.001	2.85	1.18	0.224
Genetic counselling helps expecting parents choose the eye colour of their children- Inaccurate	3.084	1.07622	1.88	1.27	<.001	1.41	0.79	<.001	1.09	0.37	<.001
Genetic counsellors must receive a lot of special training to do their job- Accurate	3.366	0.82917	3.86	0.61	<.001	3.59	0.61	<.001	3.47	0.96	0.295
Genetic counsellors advise women to get an abortion when there is a problem- Inaccurate	2.623	1.08607	3.41	1.1	<.001	1.59	0.83	<.001	1.41	0.83	<.001
Genetic counselling can help cure genetic problems- Inaccurate	2.111	0.99593	2.86	1.38	<.001	2.37	1.07	0.004	2.28	1.14	0.153
I would trust the information provided by a genetic counsellor	3.257	0.67951	3.84	0.48	<.001	3.19	0.66	0.232	3.49	0.69	0.002
Genetic counselling is in line with my values	3.128	0.816	3.59	0.92	<.001	2.88	0.82	<.001	3.42	0.82	<.001

Significance level $\alpha=0.05$, $p<0.05$ indicates the difference between the means are significant, $p>0.05$ indicates the difference between the means are not significant.

Knowledge of Genetic counselling

The third section analyses the knowledge of the purpose of GC through a series of accurate and inaccurate statements. The knowledge score ranged from 19-42 with the mean score being 30.131. It was found out both groups of people who were familiar and not familiar had almost similar average knowledge scores of 29.75 and 30.67 respectively as shown in Table 3. Both males and females had the same average knowledge score of 30.14. There were only slight differences in average knowledge scores between the demographic variables as shown in Table 3.

Out of 11 questions that were asked to measure the knowledge, 4 inaccurate statements were agreed with the average mean being 2.64, 2.74, 3.08 and 2.62 respectively as indicated in Table 7. "Genetic counselling is a service mainly for pregnant women". "Genetic counselling is only useful to a small group of people with rare diseases". "Genetic counselling helps expecting parents choose the eye colour of their children". "Genetic counsellors advise women to get an abortion when there is a problem" were the 4 inaccurate statements that were agreed upon by the population. The status of other statements were depicted in Table 7. The Knowledge score of different statuses of familiarity was compared and analysed in Table 4 and Table 5 using One-way Analysis of Variance (ANOVA) ($\alpha = 0.05$) which showed varied results when 4 categories of familiarity were clubbed together in different combinations.

Category 1- familiar, somewhat familiar, very familiar and not familiar. – showed that the difference between the means was significant. **Category 2-** familiar, not familiar, and somewhat familiar showed that the difference between the means was not significant with a p-value less than 0.05.

Other categories, **Category 3 (**familiar, somewhat familiar, very familiar), **Category 4** (somewhat familiar, not familiar, very familiar) and **Category 5** (not familiar, very familiar, familiar) showed significant differences as shown in Table 4. One to one comparison of the status of familiarity showed the highest significant difference between the groups "very familiar" and "not familiar" and no significant difference was found between the groups "not familiar" and "somewhat familiar" as in Table 5.

Attitude and willingness towards genetic counselling

The population had shown a positive trend towards attitude and willingness to receive GC service in future if needed. The statements were accurate and a mean score of above 2.5 was indicative of agreement with the statement. The three statements in this section had a mean value of 3.25, 3.12 and 3.28 respectively, which were well aligned towards positive attitude and willingness as depicted in Table 6.

Comparative study

The results were compared with previous works assessing the attitude and knowledge of genetic counselling in a rural population of USA[8], the Hutterite population of Canada[11], and in a hospital population of Ethiopia[12]. Table 7 shows the significance of the difference between the knowledge and attitude of the present study with all three studies mentioned above using a T-test. Except for the two statements, all other statements showed a significant difference in knowledge and attitude when compared with the Ethiopian study (with p value<0.05). Similarly, the USA study also showed a significant difference in 10 statements except for one statement. A Canadian study showed a significant difference in mean for 6 statements and the other 5 statements showed a similarity in knowledge between South Indians and Canadians as described in Table 7.

DISCUSSION

The present study is the first to investigate familiarity, knowledge, attitude, and willingness towards genetic counselling among the South Indian population. Even though most of the respondents reside in Tamil Nadu (79.01%), the population can very well represent South India because of similarities in culture, food habits, climatic conditions, geographical placement, education system and governmental operations including the health care sector. The majority of the respondents were males. Definition of genetic counselling and the role of counsellors given at the very beginning of perspective of purpose or knowledge measurement served as a main source of information for the participants to evaluate the statement. The study was not designed to represent an educated crowd but 63.17% of respondents were postgraduates and 34% were undergraduates, which does not represent the overall educated population in South India and was limited in this aspect. Since the mode of data collection was through google forms, people who had smartphones and had access to internet connections were segregated but can be considered as a group by itself as an educated population which has the scope to be compared in future studies. Another limitation was the measure of willingness to use GC in the future when needed. The hypothetical willingness measured on a scale may be different from an actual willingness to use the service in need and much more awareness measures must be taken in the country before measuring the actual willingness.

The knowledge score of this study showed a range between 19-42, which indicates that none had got all the statements wrong. The results of one way-ANOVA as in Table 5 show that the knowledge score of the 2 categories "not familiar" and "very familiar" differ significantly which is logical. No significant difference can be seen between "not familiar" and "somewhat familiar" which may indicate the need for more awareness measures to practically understand the purpose of genetic counselling even among the respondents who claimed that they were somewhat familiar with genetic counselling.

Disagreement with an inaccurate statement (<2.5) and agreement with an accurate statement (>2.5) were considered as the correct perception of purpose. 4 inaccurate statements were perceived as accurate by the population, other 7 statements had followed the correct trend. A positive attitude was shown towards genetic counselling. Few earlier population studies apart from recent studies had shown a positive attitude towards GC [14,15,16]. The comparative study between other countries depicted that Canadian study has got 5 statements inline (similar perspective) with the present study ($p > 0.05$, the difference between the mean values was not significant) followed by the Ethiopian study (2 statements) and finally USA rural population (1 statement) as seen in Table 5. According to the World Health organisation, many similar low- and middle-income countries are showing a shift in increased death rates with non-communicable diseases[17]. A similar kind of trend was observed in many developed western countries around the 1960s, which lead them to increase their focus on medical genetics services such as prenatal screening, genetic counselling, carrier detection, and new-born screening. Genetic counselling officially became a profession in the United States in 1969 and expanded internationally over the past 30 years[18,19]. According to this study, the South Indian population had reported 59.10% awareness, 4 out of 11 statements showed insufficient knowledge of the purpose of GC, knowledge score does not change

drastically in comparison with demographic categories. The percentage of the population familiar with genetic counselling in the present study (59.01%) was found to be higher when compared to the North American study which was about 50% and the Ethiopian study (30%). There were differences in the percentage of total respondents who had undergone genetic counselling in the present study (1.07%) compared to the Ethiopian hospital population which was 0.09%, 16.5% in the Midwestern United States population and 10.8% in the Hutterite Canadian population. Unavailability of such services in the mainstream health care sector or prenatal care may also be a reason for such a low number of respondents who had used the services themselves.

CONCLUSION AND RESEARCH RECOMMENDATIONS

Genetic counselling aims to help people understand and adapt to medical, psychological, and familial implications of genetic contributions to disease[20]. The population had reported significant familiarity, positive attitude, and willingness towards genetic counselling. Similar kinds of studies from other parts of the country will help in making nationwide policies and decisions. Awareness studies on GC among the affected group of people with genetic conditions will throw light on whether the concept had reached the people who are in need. Evaluation studies on neglected, preventable risk factors present among the family members of individuals affected by genetic diseases will help emphasize the importance of preventive measures like GC and testing. Educative sessions and taking up genetic counselling as a mainstream profession are needed not just in main cities but throughout the country as a service available through primary health care centres. Acknowledging the importance and need for genetic counselling as a preventive measure to reduce congenital anomalies and genetic disorders in the future will lead to drastic changes both in the health care sector and in society.

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