

Attitude of Indian mental health professionals towards genetic counseling

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Abstract

The study aimed to assess the attitudes of Indian mental health professionals towards genetic counseling. An 18- item survey was designed in English and distributed among 87 mental health professionals, with a response rate of 58%. Almost all (97%) participants showed extreme, high or moderate interest in genetic counseling. Majority had positive responses when asked regarding the importance of genetic counseling. In particular, the need for genetic counselors was strongly supported.

Keywords: *Attitude, Genetic counseling, mental health*

Introduction

Genetic counseling, a communication process, can assist with prevention and acceptance of genetic diseases and helps disseminate the findings of genetic research.¹ An important aspect of genetic research is the ability to directly take the research from laboratories to the public, referred to as, 'from bench work to bedside'.² Though genetic counseling is provided for some diseases in India, it is not systematically accessible or part of the health services.³

There have been several studies⁴⁻⁷ from other countries assessing professionals' views towards genetic counseling, and it was found that many were uncertain of their own competence to do so, but felt a huge need. It was also observed that physicians perceived that genetic counseling would be useful only when more data are available on genetic tests and therapeutic interventions are possible. In an Indian study⁸ related to Down Syndrome, it was reported that parents were not aware of any

preventive strategies or antenatal screening. Despite uncertainty in psychiatric disorders, the importance of genetic counseling cannot be negated.⁹ Genetic counselors themselves can resolve certain false beliefs regarding psychiatric disorders and replace these with positive attitudes. The WHO report¹⁰ particularly highlighted the need for genetic counseling services in developing countries. As there are very few curative therapies or therapeutic interventions available for genetic diseases, genetic counseling plays a significant role in the management of diseases with genetic risk.

Psychiatric diseases are multi-factorial and hence, genetic counseling is a complex task. However, there are many issues that can be addressed positively by genetic counseling to families such as recognizing the issues of stigma, guilt, fatalism, childbearing decisions and the affected individuals' behavior management decisions.^{9,11,12} Making meaning of these risks can assist families in coping with the diagnosis

of a mental illness in the family.¹³ More accurate risk perception can be facilitated by genetic counselors which can influence major life decisions in siblings of the mentally ill.

The present study aimed to explore the attitude towards genetic counseling among mental health professionals from India.

Materials and Method

Sample

The sample was constituted by health professionals working in the field of mental health in India.

A major part of sample was derived from the participants of an international conference (*Ethical issues and genetic counseling in mental health*) organized by the Training Program for Psychiatric Genetics in India, with support of an NIH research grant. The workshop was focused on discussing cross-cultural and other issues regarding ethics and genetic counseling among mental health professionals in India. Though speakers were from abroad, all the participants were from India. The survey questionnaire was distributed to all the mental health professionals from India who were conference participants (N=55).

In addition, the survey was also distributed among mental health professionals working in different hospitals of Delhi (N=32), which included psychiatrists, junior doctors working in psychiatry departments, psychologists and researchers working in mental health.

Before administering the survey, the purpose was explained to participants. Participants were told that the survey would assess their attitudes regarding genetic counseling in psychiatric illnesses. The survey was anonymous, so ethics committee permission was not required. The study was IRB exempt per University of Pittsburgh's rules. Respondent's anonymity was respected.

Survey

An 18-item survey was designed to study the attitudes of mental health professionals towards genetic counseling for mental illnesses. The survey consisted of four demographic questions and fourteen attitude questions. The first, ninth, tenth, thirteenth and fourteenth questions were multiple-choice, consisting of four choices each and remainder had 'yes', 'no' or 'don't know' responses.

The questions assessed attitudes of the professionals regarding genetic counseling for psychiatric illnesses. There were also questions about their knowledge of genetic susceptibility and use of family history in risk perception. Participants were asked how the information regarding family history helps in disseminating genetic aspect of these diseases in clinical practice. They were also asked that who should provide genetic counseling, and who should make genetic testing decisions. Descriptive statistics have been used to present results.

Results

The response rate was 59.7% (n=52), comprising of 36 mental health professionals from conference and 16 mental health professionals working in different hospitals in Delhi. Of these 52 participants, six had to be excluded due to incomplete surveys. Of 46 completed surveys, 68.4% were males and 31.6% were females. Majority of participants were psychiatrists, followed by medical graduates working in various hospital psychiatric units, and psychologists.

The findings are shown in Table 1. Most participants were moderate to highly interested in genetic counseling. (48.5% moderate interest, 45.5% high interest and 3% extreme interest).

Who should provide genetic counseling?

Majority (75%) suggested that genetic

Table 1: Summary of questionnaire responses

| Question | Yes | No | Don't know |
|--|-------|------|------------|
| Do you think genetic counseling is a helpful tool in helping families at risk of psychiatric illnesses? | 100% | 0% | 0% |
| Do you think genetic counseling should be available for mental disorders? | 95.2% | 2.4% | 2.4% |
| Do you think genetic counseling can help in understanding patho-genesis of disorder? | 85.4% | 4.9% | 7.3%* |
| Do you think genetic counselors can work with the affected family to facilitate accurate and useful risk perception? | 97.6% | 0% | 2.4% |
| Do you think genetic counseling can help to combat stigma in major mental illness? | 85.4% | 9.8% | 4.9% |
| Do you think genetic counseling can help in removing myths related to major mental illnesses? | 82.9% | 9.8% | 7.3% |
| Should genetic counseling be offered to siblings of affected patients? | 90.2% | 2.4% | 2.4%† |
| Do you routinely take the family history of the patients? | 97% | 3% | — |

*1 missing; †2 missing

counselors should be given the responsibility of providing genetic counseling. However 15% felt that the psychiatrist was capable of providing this service.

Who should make genetic testing decisions?

About 60% respondents felt that patient and health care provider should make genetic counseling decisions jointly, and these should be evaluated on a case-by-case basis. However, 21% opined that the decisions should be made by patients only.

Is it ever appropriate to decline to perform genetic testing (prenatal/ presymptomatic)?

Though these services are not available in the psychiatry, 44% of participants felt that if genetic testing is available patients have right to decide for themselves.

How do you use family history information on psychiatric diseases?

Most of the participants used the family history (65%) and about 24% were willing to

send their patients for genetic consultation.

In the last year how many articles, books or medical journal publications have you read?

This question had varied answers. Of all respondents, 36% had read between 1-10 articles, 22% read 10-19 articles and 19% read 20-29 articles.

Discussion

The survey shows that there is overwhelming support for genetic counseling and testing and a willingness to incorporate these services into health care services in India. Various earlier surveys in other countries have been skeptical about including these services in their health care systems especially in psychiatry. ^{5, 7} The ambivalence might be the result of inadequate knowledge of genetics and genetic testing. Lyus¹⁴ studied attitudes of patients suffering from schizophrenia and their relatives' attitude towards genetic counseling. The participants felt a need for genetics but limited availability of genetic counseling was worrisome for the participants. Mountcastle-

Shah et al⁵ rightly concluded that large scale, collaborative, practice based evaluation is feasible if physicians actively participate in research in safety and effectiveness of genetic testing. This can educate the physicians on genetics.

The study suggests that the Indian mental health professionals appear to be more open to the idea of genetic counseling, though they think that they are not competent enough to provide genetic counseling themselves. When asked about refusing genetic testing, majority of them said that patients had a right to do so. This supports a non-directive approach and attitude to genetic counseling which has accompanied the development of genetic services in Europe and North America.

Family history was utilized by almost all (97%) of the participants. It may be because many mental health professionals use family history in understanding diagnosis and prognosis of mental disease. This information is also useful in marriage counseling also which is an important query of patients and their families in India.

The discipline of mental health and neurological sciences in India faces the toughest challenge of human resources shortage, up to 80% for doctors, psychiatric nurses and psychologists. As these professionals are overwhelmed by their own work, they may not be able to do justice to counsel their clients in genetic aspects of psychiatric diseases.

At present, there are several institutes/centers throughout India, especially in metropolitan cities where sufficient technological facilities are available for the detection/diagnosis of various genetic diseases along with the detailed investigations as well as genetic/marriage counseling.¹⁵ Counseling is typically provided by medical doctors. Genetic counseling in the west is provided exclusively

by genetic counselors who are mostly health professionals having either a graduate or a postgraduate degree in medical genetics and counseling skills. However, in India, counseling is hardly a well-developed field. Genetic counseling at best may be part of the consultation with a family doctor.

The study has several limitations. It is a preliminary exploratory study for Indian setting, with a relatively small sample size. Most of the participants were delegates of a conference on genetic counseling and ethics in genetic research; therefore, the overwhelming positive response could be the result of pre-existing inclination or educational discussions from the conference. Regardless, the majority of respondents were open to the idea of incorporating genetic counseling programs and welcoming the new profession of genetic counseling in India.

More research in this area can assist the design of clinical services and may inform regarding the strategies that determine the creation and acceptance of genetic counseling services.

Acknowledgement: We thank our study participants, clinical recruiters and data specialists of our research groups. This work was supported by grant from Fogarty D43 TW006167.

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Source of support: The study was supported by a grant from Fogarty D43 TW006167

Conflict of Interest: None declared

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