



RESEARCH ARTICLE

Transformation to telephonic genetic counselling during SARS-CoV-2 pandemic: challenges and suggested protocol in Indian scenario

SHAILESH PANDE*, SHINY BABU, HARSHWARDHAN GAWDE and NEHA MINDE

Genetic Research Centre, ICMR-National Institute for Research in Reproductive and Child Health, Jehangir Merwanji Street, Parel, Mumbai 400 012, India

*For correspondence. E-mail: pandes@nirrh.res.in.

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Abstract. Genetic counselling (GC) is a process of communicating and educating patients and/or their family members diagnosed with genetic abnormalities. Ideally, GC is offered in-person, physical presence of both the counselee and the counsellor. However, COVID-19 pandemic and new norms of social distancing precluded undertaking GCs. In the wake of this, Genetic Research Centre at ICMR-NIRRH, Mumbai, arranged virtual sessions for GC. Here, we describe our experience of initiating genetic counselling services on virtual platform. This report presents the challenges faced by the genetic counsellors as well as the counsees and suggests a protocol to be followed during tele-genetic counselling. It is based on the retrospective data of 65 cases that were counselled from July 2020 to September 2020 which was the period of lockdown and restriction. Although a few issues emerged during the process of GC, virtual tele-counselling was a preferred option due to social distancing, lack of public transport facilities and COVID-19 specific restrictions. Effective virtual follow ups saved time, energy and finances of providers as well as clients. This article presents providers' experience of the process and some recommendations in Indian scenario.

Keywords. COVID-19; genetic counselling; SARS-CoV-2; telephonic counselling; virtual counselling.

Introduction

Genetic counselling (GC) is a process of communication and education to patients suffering from genetic disorders and their parents/family members. It helps them gain better understanding of genetic disease, underlying causes, risks associated, and available disease management options and also make them aware of the severity of the risks, limitations and benefits of tests, for appropriate test selection. Primarily, during the GC sessions, focus is on giving important information to patients without any bias and in nondirective manner, to help them in decision making. The clinicians usually refer their patients to a medical geneticist or a genetic counsellor for their expertise in dealing with information sharing and handling the psychological trauma faced by family members due to new information. As the lifetime management of a genetic disorder is often a financial burden for the family, the counselor has to offer compassionate hearing and long term follow up to the patients (Sharda *et al.* 2020). Ideally, genetic counselling is offered in-person sessions in physical presence of both the counselee and the

counsellor. Telemedicine facilities are well established and routinely accessed for distant patient consultation in developed countries. However, such facilities are lacking in middle and low income countries globally. Additionally, telephonic or virtual genetic counselling was not permitted by local governing authorities before the SARS-CoV-2 pandemic. Since after the approval by the governing authorities, a virtual mode of genetic counselling has been accepted widely in the current situation. In countries like India, the virtual genetic counselling is now possible.

Materials and methods

During the lockdown (March 2020–September 2020), centre was following the COVID-19 protocol strictly, therefore GC sessions in-person were not possible. Patients who expressed an urgency for GC session were called telephonically and asked about the feasibility of videoconferencing. Those who were willing to have a virtual GC session were asked to e-mail their referral letter, reports, photographs of the index

case, and other important clinical history documents on department e-mail ID, to ensure confidentiality. By mutual agreement, a suitable timing was decided for counselees and genetic counsellor for GC sessions during the working hours of the clinic. The virtual counselling clients were requested to be present with their spouse so that no history is missed by the counsellor and no information is missed by the counselee.

Virtual counselling session was based on WhatsApp video calling, as all patients had easy access to it. At the beginning of the session, the counsellor introduced himself and the staff present (nurse and social worker). The couple was requested to be in a separate room or corner of the house, to ensure privacy and nondisturbance. Couple was verbally assured about confidentiality of the information shared by them with the genetic counsellor and no session was recorded.

A standard set of questions was asked at the beginning to initiate the session. Baseline information was sought from the clients, i.e. educational qualification, occupation, span of married life, consanguinity, history of detection and diagnosis, tests carried out so far etc. Flow of genetic counselling was altered as per the requirement of the case. At the end of the session, patients were asked whether they have understood and had any more queries. They were also asked to summarize the discussion in their words to assess information gaps.

Notes and prescriptions from virtual GC were sent on WhatsApp or e-mail IDs after the session got over. Also all observations were recorded in the case file prepared separately. File registration number was communicated to the patients after the session.

Results

A sharp decline in the number of cases attending clinics at genetic research centre was observed due to the direct impact of COVID-19 pandemic (figure 1). Considering the feasibility of virtual consultation, urgency and preference by the patients or their relatives, GC was planned. A total of 65 genetic counselling sessions were undertaken during the period from July 2020 to September 2020. Genetic counselling was offered to all the 65 cases, of these 38 (58.46%) sessions were live (physical) and 27 (41.54%) virtual (video based WhatsApp calling) sessions were arranged. Of the 65 cases who underwent genetic consultation, 31 (47.69%) were new cases and the rest 34 (52.30%) were follow-up cases. In the 34 follow-up cases, around 20 (58%) patients and in 31 new recruited cases, around 29 (93.54%) patients told that they themselves would have cancelled the physical appointment due to fear of SARS-CoV-2 infection. All the 27 (100%) patients who attended virtual counselling conveyed that they felt this was a convenient method, as they saved their time, money and energy required for travelling. Also they felt that they got individual attention from the

geneticist. Patients also expressed that during the session, they were free from stress caused due to pandemic, because they could avoid the exposure to get COVID infection by visiting the health setting premises. For the counsellor, conducting virtual sessions for 26 (97%) patients were easier. Of the 27 patient, one (3%) was not having smart phone facility and hence had to take the help of local health care worker.

All counselees (100%) shared that they were satisfied by the information received for their queries. Those who were from outstation felt that teleconsultation is a better option. Those staying nearby expressed that they would prefer to come in-person after the ease of restrictions. Also from the perspective of the provider, it was felt that the reach out was widened due to teleconsultation during the pandemic period.

Challenges faced by the counsellor and counselees

Basically, the geographical barriers for computer networks, poor connectivity issues resulting into call drops, power shutdowns were the technological challenges faced by the counselees. Establishing virtual set up in small houses with more number of family members with lot of background noise, family pressure/interference of elders or extended family members were also the client specific challenges. In one case, requirement of a third person was felt to handle virtual set-up. This can be a cause for a major breach of confidentiality, in comparison with in-person counselling.

Lack of personalized contact, lack of digital literacy of the clients; difficulty in clinical examination in all cases (100%), difficulty in understanding the local dialects were the major challenges for the counsellor. In one case, a local doctor was involved as an interpreter in the GC process. Study was considered under exempt category from review and was approved by the Institutional Ethics of ICMR-NIRRH, Mumbai.

Proposed protocol for telephonic or virtual genetic counselling

(i) Allotting a time slot for effective use of time by clients, sharing link a day before. (ii) Defining the scope and limitations of genetic tele counselling service. (iii) Asking the client to e-mail the history, i.e. related reports, pictures, reference letters prior to the appointment date. (iv) At the beginning of the session, taking verbal consent of clients / index cases / parents for recording, as recording of the GC session may be useful for correlating the findings. Consent for future use of photographs, documented history, videos shared by the patient should be taken. (v) Introducing the staff who is present for the session. (vi) Pedigree drawing and recording the information on case paper. (vii) Emailing

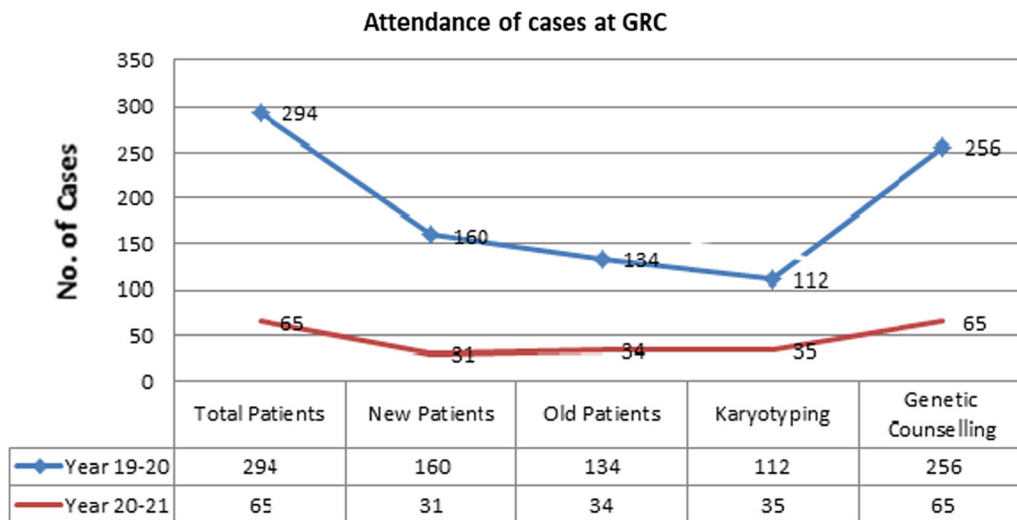


Figure 1. Attendance of cases at Genetic Research Centre. In the following chart, decline in number of cases appearing for GC in the year 2020–2021 is seen clearly, as a direct impact of pandemic as compared to the year 2019–2020.

the prescriptions for further testing as needed or using WhatsApp for the same. All of the data supporting the results presented in this paper are available on request.

Discussion

We did not come across any study with reference to challenges in offering genetic counselling in virtual mode in any resource poor settings in India. The study presents the challenges faced by the genetic counsellor as well as the counselees during the attempt of tele-genetic counselling. Adjustment to online counselling may be awkward initially, but, with careful preparation, tele-health services can be an equally effective alternative for in-person sessions. All the patients who received the counselling were satisfied by the information received and could follow it well. They asked the questions in reply and clarified their doubts. Of the 27 cases that underwent genetic consultation, all (100%) were comfortable and conveyed that virtual method was good enough and they would prefer to follow up this in future. Around 58.46% follow up cases and 93.54% cases thought that if this mode of GC were not adopted they would not have consulted because of the fear of COVID-19. We also noticed that in cases such as advanced maternal age, delaying the genetic counselling session due to pandemic would have been a major loss of important time. In fact, we have noticed that it was a very timely and appropriate intervention, especially in prenatal cases, considering the legal limits of termination of pregnancy in Indian scenario, if a foetal genetic abnormality is detected in prenatal diagnosis. The remote healthcare has become an extremely essential tool during pandemic time. Patients using tele-health services reported high level of

satisfaction due to time saving nature of the method and appointments were scheduled at the convenient timings (Hawrysz *et al.* 2021). Genetic counselling using telephone can be time saving, interaction focussed, can ensure privacy and confidentiality are some of the advantages but missing out non-verbal clues, is one disadvantage reported in the study (Wang *et al.* 2000). Study reported telephone model can be at par or better than in-person counselling and can be accepted as a standard mode for counselling except some areas needing improvement such as drawing a pedigree (Wang *et al.* 2000). Filling of feedback format at the end of the session can be helpful to improve the tele-health services. Guidelines to improve satisfaction of the patients can be prepared by the researchers. Correlation of demographic factors with patient satisfaction should be considered (Hawrysz *et al.* 2021). Review paper by Gordon describes how technology has been used historically in genetic counselling for pedigree construction, analysing genetic risk, review and collection of patient’s information, diagnostic evaluation and documentation. Challenges faced while utilizing apps are specific to both discipline and technology. Technology can appear to be less ‘humane’ or ‘personal’ and hence can be less convincing. There are contradictory thoughts in favour or not in favour of using technology in practice. Those favouring the use of technology support integrated approach of technology with practice is required. Safeguarding the rights and privacy of the clients is very much a concern if reliability of apps is a concern (Gordon *et al.* 2018). A study conducted on women’s telephone counselling is best suited for those women whose diagnosis is well-established and those who do not have major need for psychosocial support but in case of emergence of considerable complexity of psychosocial issues alternate strategies/models should be

thought of. Also the level of satisfaction may differ in case of paid services (Zilliacus *et al.* 2010).

Conclusion

Virtual counselling may not be possible for all clientele across India but for some of them it will be helpful. Alternative strategies such as using telephone, video calling, group video counselling approach if possible (in case of similar conditions) and if acceptable to clients, using different apps, keeping the information, education and communication (IEC) material handy, which can be put up on website group counselling among similar cases, use audio-visual clips can be done for reinforcing the counselling inputs can be utilized to save resources. There is lack of studies about feasibility of virtual sessions in geographically out of reach areas in India. Additional studies about their impact and acceptability in Indian conditions are needed. In the long run, establishing wi-fi enabled hubs in public health settings for super speciality consultations can prove beneficial for resource poor settings. Also effective follow ups can be possible virtually saving time, energy and finances of providers as well as clients. Considering the paucity of medical geneticists and genetic counsellors in low and middle income countries, developing culture specific standardized protocols or guidelines for virtual genetic counselling sessions in the payment free setups might help to offer the genetic services to the needy.

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Authors' contributions

SP, SB, HG and NM contributed for the development of this manuscript. SP conducted the tele counselling sessions and SB organized the sessions. HG was involved in preparing karyotyping reports and SB prepared the reports. SP prepared the final draft of the manuscript. NM was involved as an observer in the sessions and prepared the initial draft of the manuscript. All authors have read and approved the final version of the manuscript for submission.

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