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SPECIAL ISSUE

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Telegenetics: The experience of an Indian center (Centre for Human Genetics) during the COVID-19 pandemic

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Abstract

Because of the lockdowns and restrictions placed on non-emergency medical services due to the COVID-19 pandemic, we were prompted to set up telegenetic services for patients and families with genetic disorders. Genetic medicine poses special challenges because the unit of consultation and counseling is often the family and not just the individual. We describe here our experience over eight months in 2020 in evaluating 539 families with genetic disorders on a virtual platform. Patients from urban and rural districts of Karnataka and neighboring states received telegenetic consultation. Families were phoned by genetic counselors 14–28 days after the initial consultation to measure feedback. One member of each family was invited to complete a modified 9-item Telehealth Satisfaction Scale (TeSS scale). Of 293 respondents, approximately 87.3% reported satisfaction with the visual and audio quality of online contact and 86.7% on saving travel time and expenses. A shorter waiting time for appointments as compared to in-person appointments in the previous year was seen in approximately 90%. Nearly 87% reported satisfaction with online genetic consultation; however, 74% of these indicated a preference for a face-to-face appointment. The reasons for this included a cultural perception of confidence instilled by meeting medical specialists in person. Telegenetics presents unusual advantages in India because of the high usage of smartphones, unlimited Internet data as a feature of most Internet plans, free web-based video applications, and digital payments. We suggest that telegenetics may be an alternative in providing a hybrid model of care in non-emergency situations especially where resources are limited.

KEYWORDS

COVID-19, developing country, Genetic services, telegenetics

1 | INTRODUCTION

With the spread of the COVID-19 pandemic, access to health services of all kinds has been severely challenged everywhere. Medical professionals in all specializations including genetic medicine have struggled to keep their services going. Our center, located in Bengaluru, is a tertiary clinic offering genetic services to approximately 2000 families annually. We have adopted telegenetics as a means of connecting with patient families during these difficult times. We describe here our experience in providing telegenetic services and highlight some of the advantages and challenges. After consultation, 293 consultands consented to give feedback about their satisfaction with telegenetics. They were interviewed by telephone using a 9-item structured questionnaire—The Telehealth Satisfaction Scale (TeSS scale).

1.1 | Background and the need for telegenetic services in India

Telemedicine uses technology and telecommunications to provide health care and education over a distance (Smith, 2007). In India, it was made possible by the launch of the Indian National Satellite (INSAT) by ISRO (Indian Space Research Organization) in 2001 (Pilot Project on Telemedicine—ISRO, 2000). Telegenetics, a specialized branch of telemedicine, has been described as 'comprehensive genetics services to reach children and families when travel, distance, and shortage of genetics professionals interfere with access by utilizing interactive video and a secure high-speed connection, genetic counselors can "virtually meet" with a patient at a regional clinic or hospital in real-time' (National Society of Genetic Counselors, USA, 2019) (How to Incorporate Genetic Counseling, 2020).

There are approximately 7,000 known rare disorders, and nearly 80% of them have an underlying genetic basis (Rare Diseases, 2019). It is estimated that there are about 70 million individuals affected by rare diseases in India (Rare Diseases India, 2021). There is an acute shortage of genetic specialists in India, with fewer than 100 trained clinical geneticists and a handful of qualified genetic counselors (Taneja et al., 2020). India has a population of 1.3 billion people (India population 2020—StatisticsTimes.com, 2020), and 68.4% of whom are in rural areas (Chellaiyan et al., 2019). Remote access to specialist health care in India is available to very small numbers (Bagchi, 2006). During the initial two months of the national shutdown and periodic short, state-wide closures to contain the spread of COVID-19, only emergency medical services were able to operate in a majority of clinics and hospitals. Many genetic clinics and hospitals were forced to cancel appointments of all non-emergency cases. It is often perceived that there are no emergencies in medical genetics. However, examples to illustrate the contrary include a pregnancy where a definitive intervention and genetic test may confirm the fetus to be affected or not, a newborn with an inborn metabolic disorder (IMD) requiring early neonatal diagnosis and intervention to prevent neurological handicap and death, and a child born with ambiguous genitalia requiring a genetic test for gender assignment at the earliest. In these examples, genetic testing and prompt intervention are required. Therefore, genetic services need to be ongoing despite the current pandemic and telegenetics is a means of consultation to assist families in need of genetic interventions.

1.2 | Experience in implementation of telegenetics in developed countries

In 2012, a review of telegenetics services in the UK and other European countries noted that the majority of the consultations were between an expert and a patient located in a distant clinic (Hilgart et al., 2012). These consultations included a range of cases including pediatric, prenatal, and hereditary cancers. The experiences were measured by a quantitative pre- and post-counseling questionnaire, including true/false questions, Likert scale questions, and open-ended questions for free-text responses, which were largely positive. The shortcomings mentioned included difficulty in establishing rapport and some difficulties with the use of the technology involved in telemedicine. Many of the studies reviewed were comprised of small numbers which makes it difficult to draw conclusive opinions. In another review of reviews from multiple centers, it was reported that telegenetics added to the efficiency in providing medical services (Ekeland et al., 2010). Qualitative assessments in this study reported 21 reviews highlighting conclusive success and 18 reporting promising but incomplete evidence of telemedicine effectiveness. The utility of videoconferencing in obtaining detailed family and medical history and in accurately diagnosing pediatric genetic and dysmorphic disorders are highlighted by Stalker et al., 2006. The advantages noted were shorter waiting times for appointments and the maintenance of the child's privacy. However, as this study involved pediatric dysmorphology, the consultations followed a hybrid model with an online consultation followed by a face-to-face appointment. Even prenatal genetic counseling has successfully been done through telegenetics (Abrams & Geier, 2006). Recent reports from Australia and the USA note that telegenetics has the potential to evaluate individuals remotely, which reduces travel and other costs with an increase in patient satisfaction levels (Hilgart et al., 2012; Hopper et al., 2011; Stalker et al., 2006). From India, the single previous reference to telegenetic consultation was an abstract outlining the positive experiences from counseling *BRCA1*-related breast cancer families by telephone and by video consultation (Dawood et al., 2019).

What is known about this topic

Telegenetics has been used in developed countries for genetic counseling connecting counselors from a center of expertise to peripheral health centers mostly through videoconferencing.

What this paper adds to the topic

This is the first detailed report from India where telegenetics has been used to connect centers of expertise to families in their homes. The unique local advantages, methodology, and challenges have been described.

2 | METHODS

2.1 | Procedure

We describe our experience over eight months (May 2 to December 31, 2020) at the Centre for Human Genetics. This center, located in Bengaluru (population of 12.6 million) (India Population (2020)—Population Stat, 2020), is served by three clinical geneticists

and three genetic counselors. In the 539 families seen for telegenic consultation, one or more members were affected ($n = 333$) or at risk ($n = 206$) with one or more genetic disorders. Most probands were referred by physicians; however, a few ($n = 5$) were self-referred. In the majority, the proband and closely related family members were present during the consultation, which is culturally the norm in Indian society. Around 80% were from the state of Karnataka (67 million population) (Karnataka Population 2011, 2020) and 20% from other states.

The Medical Council of India (MCI) formulated telemedicine practice guidelines in early 2020 (MoHFW, 2020). Based on these guidelines, we began telegenetics services using the ZOOM application. A pictorial instruction manual in English was created and translated into other languages depending on the patients' needs (Figure 1).

Two sessions of contact with the referred family were usually made. At first, all families were contacted via telephone by a genetic counselor for an introduction, obtaining a family history and clinical details (clinical, operative, or other medical records). Instructions to connect by ZOOM were sent by e-mail to the family. The second contact by ZOOM, with the clinical geneticist and the counselor, was scheduled within the next day or two. A single consultation lasted 40–45 min. Where indicated, blood samples for genetic testing (for chromosome studies and molecular diagnostic testing including exome sequencing) were collected from home by phlebotomists from the testing laboratories, which has become the norm in the changed circumstances. The signed informed consent and request form for genetic testing were completed by the counselor and emailed to the laboratory after consultation. Payments were collected for consultation and laboratory tests using online portals, described under discussion. A post-consultation written summary was shared by e-mail with the family and the referring doctor. In review appointments, genetic results were emailed as a soft copy to the family prior to the appointment and the results were discussed by the clinical geneticist in detail during the consultation. The entire process is denoted in a cartoon in Figure 2.

Around 14–28 days after the online consultation, the consultands were called via telephone for feedback about their telemedicine experience. Based on a 10-item Tess scale (Morgan et al., 2014), we used 9-item questionnaire to measure patient satisfaction. A Likert scale was used to mark responses (1 = poor, 2 = fair, 3 = good, and 4 = excellent). Higher marking on the scales indicates a larger degree of satisfaction. Scores 3 and 4 were combined to indicate a high measure of satisfaction: Table 1.

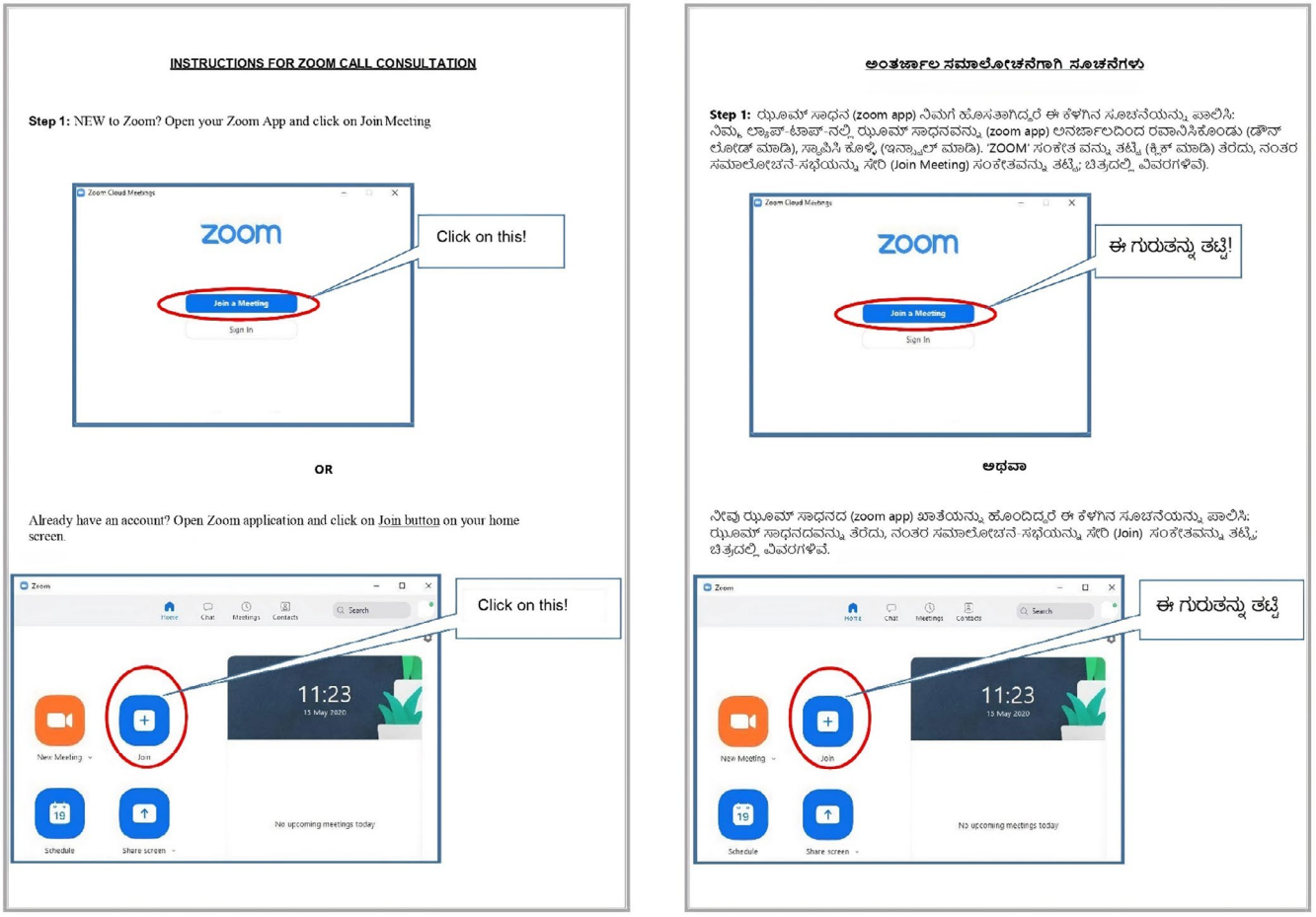

FIGURE 1 Format of the instruction details shared with the family in advance of consultation by E-mail

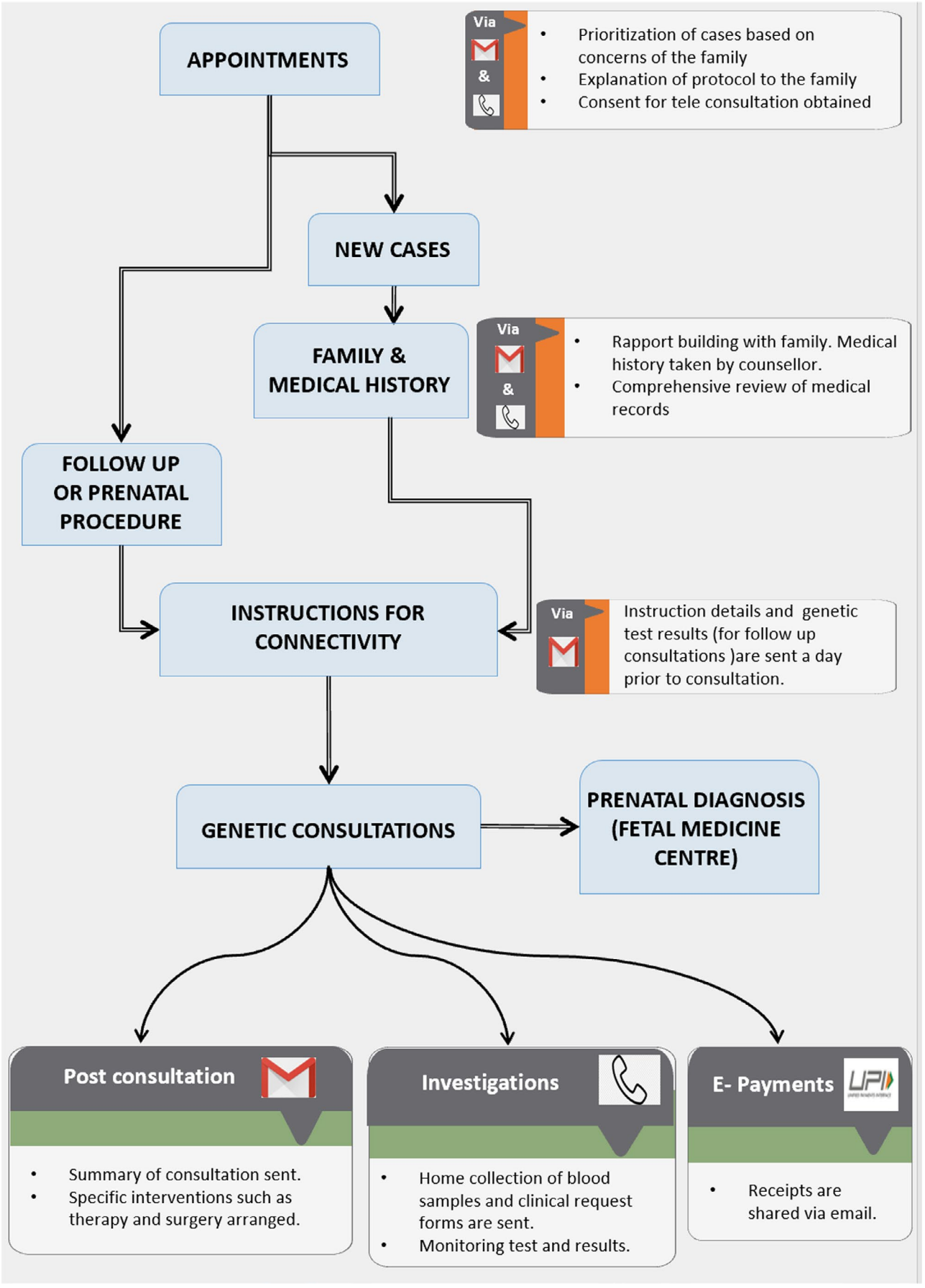

FIGURE 2 Workflow chart to describe the process from referral to post-consultation

TABLE 1 Responses of 293 individuals to a TeSS modified questionnaire measuring scores of satisfaction of the telegenetics experience

S. No	Questions	No. of Cases (*N*)	Percentage and No. of Cases for Score 1	Percentage and No. of Cases for Score 2	Percentage and No. of Cases for Score 3	Percentage and No. of Cases for Score 4
01.	How satisfied were you with the voice quality of the equipment?	293	*n* = 0	12.6% (*n* = 37 cases)	61.4% (*n* = 180 cases)	25.9% (*n* = 76 cases)
02.	How satisfied were you with the visual quality of the equipment?	293	0.3% (*n* = 1 case)	14.3% (*n* = 42 cases)	61.8% (*n* = 181 cases)	23.5% (*n* = 69 cases)
03.	How satisfied were you with the personal comfort of using telegenetics?	293	0.7% (*n* = 2 cases)	15.4% (*n* = 45 cases)	61.8% (*n* = 181 cases)	22.2% (*n* = 65 cases)
04.	How satisfied were you with the ease of connecting to teleconsultation?	293	1% (*n* = 3 cases)	19.5% (*n* = 165 cases)	56.3% (*n* = 165 cases)	23.2% (*n* = 68 cases)
05.	How satisfied were you with the length of time for connecting/ re connecting?	293	2% (*n* = 6 cases)	17.4% (*n* = 51 cases)	57% (*n* = 167 cases)	23.5% (*n* = 69 cases)
06.	How satisfied were you with the amount of time given for consultation?	293	0.7% (*n* = 2 cases)	15.4% (*n* = 45 cases)	58.4% (*n* = 171 cases)	25.6% (*n* = 75 cases)
07.	How well was your privacy respected?	293	0.7% (*n* = 2 cases)	14.3% (*n* = 42 cases)	63.8% (*n* = 187 cases)	21.2% (*n* = 62 cases)
08.	How much would you prefer face-to-face consultation over virtual platform?	293	3.1% (prefer virtual consultation) (*n* = 9 cases)	22.9% (no specific preference) (*n* = 67 cases)	56.3% (would like face-to-face consultation, but satisfied with virtual contact) (*n* = 165 cases)	17.7% (definitely prefer face-to-face consultation (*n* = 52 cases)
09.	How satisfied were you with the cost effectiveness of teleconsultation?	293	1% (*n* = 3 cases)	12.3% (*n* = 36 cases)	58.4% (*n* = 171 cases)	28. 3% (*n* = 83 cases)

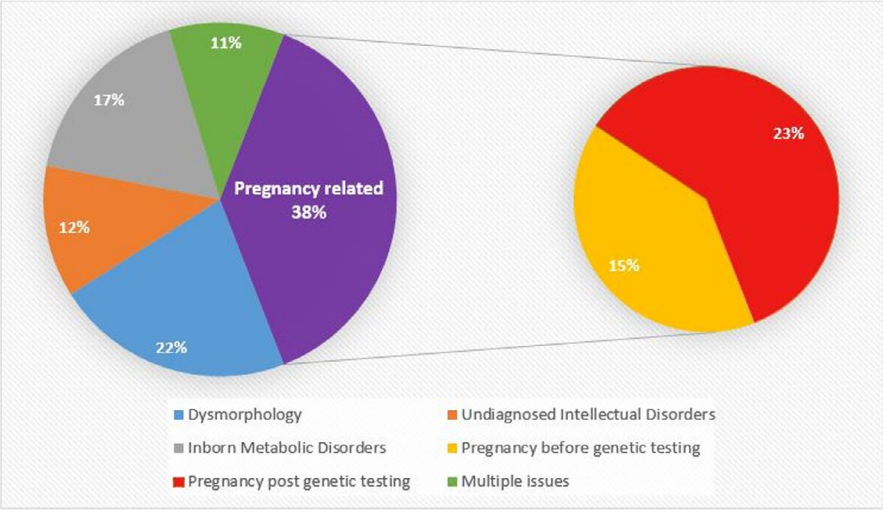

FIGURE 3 Distribution of 539 cases evaluated from May 2 to December 31, 2020

2.2 | Participants

Five hundred thirty-nine consecutive families were referred by other specialists to our center and assessed from May 2 to December 31, 2020 were included. In each consultation, a trainee clinical geneticist and counselor participated in person or virtually as observers with the consent of the family. After the assessment, they were classified as having one of several groups of disorders (Figure 3). Approximately, a fortnight to a month after consultation families were telephonically contacted by genetic counselors to measure feedback. Two-hundred ninety-three (49.4%) consented to answer a 9-item structured modified questionnaire measuring satisfaction scales in telemedicine (TeSS scale, Morgan et al., 2014).

3 | RESULTS

3.1 | Participant characteristics

Five hundred thirty-nine consecutive families were assessed over an eight-month period from May 2 to December 31, 2020. (Figure 3). Around 10% of these required translators (from English to regional language) who were often relatives or friends picked by the family. The largest number of patients counseled had pregnancy-related issues (206 cases, 38%). Of these, 83 families (15.3% of the total) had an ongoing pregnancy with either a previously affected child with a genetic disorder, an abnormal ultrasound scan with an identified fetal abnormality, or an age-related risk of a genetic disorder in the gravid lady. One hundred twenty-three (23%) families came for a consultation having had genetic testing in pregnancy done elsewhere and requiring an explanation of ultrasound scan findings and interpretation of genetic results. This is usually due to a paucity of genetic counselors in centers offering prenatal tests. Inborn metabolic disorders (IMDs) were diagnosed in 17% of referrals to the telegenetics clinic. Twenty-two percent had a child with multiple congenital anomalies of dysmorphic facial features. Parents assisted in showing parts of their child's body to the camera, and a dysmorphic diagnosis was possible in 31 affected individuals. This included a case of Oculo-Dento-Digital Dysplasia (ODDD) and another with Ohdo syndrome, two rare dysmorphic syndromes. One limitation faced by the clinician was an inability to complete full examination such as anthropometry or motor examination in around 20% of children. In 11% of cases, two or more disorders were concurrently diagnosed in the same family. Carrier status of cystic fibrosis and Brugada syndrome both identified in the same individual by exome sequencing initiated through a telegenetics consultation for preconceptional counseling is an example.

3.1.1 | Costs saved

In the families that were provided teleconsultation, an estimate of travel expenses saved was calculated. An average cost of ₹12/km (1$=Rs.73, July 2021) was used (the usual cost of travel by public transport, including Ola, Uber, and other private taxi services) to calculate the round-trip distance required to be traveled for consultation. For a family that would have required an overnight stay, a nominal charge of ₹500/family/day was included in the calculation. As a majority of patients referred to our clinics belonged to the lower socioeconomic strata (class IV and V on Kuppuswamy socioeconomic scale, Saleem & Jan, 2021), the travel and overnight estimates were at the lowest level of expenses likely to be incurred. Based on these calculations, the average cost savings per consultation was about ₹1,000 ($13.69). This, in addition to the travel time and days saved, was significant. Overseas patients (seven) and families from distant states (ten) were not included in this calculation.

3.1.2 | Responses to the TeSS

Out of 539 families, individuals from 293 (54.3%) families consented to answer questions regarding their satisfaction with telegenetics. In

India, medical appointments for children are invariably attended by both the parents. Of those who agreed to participate in the survey, it was the male head of the family in the majority (father or husband, 61%), and in the remaining, it was the mother of the proband who answered the questions. This was based on who was available at the time of contact. Approximately 87.3% of respondents reported satisfaction with the visual and audio quality of online contact and 86.7% on saving travel time and expenses. Nearly 87% reported satisfaction with online genetic consultation. Interestingly, 74% of these indicated a preference for a face-to-face appointment. The majority (249 cases, 85%) reported satisfaction with their level of privacy is respected. 86.7% (254 patients) were satisfied with the cost of travel and stay saved with a virtual consultation. Individuals who did not perceive the consultation as cost-saving were those residing in the same city who nevertheless had to pay for their genetic tests (13.3%).

3.1.3 | Connectivity issues

Forty-seven individuals (nearly 16%) reported some difficulty in connecting to the ZOOM teleportal as they were using an online application for the first time. Around 19% had an interruption of a session lasting a few minutes due to a power outage at the family end. The majority were able to reconnect successfully. Most of these had successful consultations. Two individuals were reluctant to connect from home as they were concerned about the lack of privacy in a joint family. Consultation for a few families (<10) with a poor appreciation of technology was over WhatsApp video call. Around 10 families had to travel a short distance from home for better network coverage including one family who had their consultation in their car parked in the nearby town center.

4 | DISCUSSION

Five hundred thirty-nine families with genetic disorders had telegenetics consultation over an eight-month period in their own homes. Each family that was counselled was counted as a single (539 had at least one consultation, and 180 (33%) had one or more review appointments). The majority of consultations over ZOOM and supported by e-mail were deemed successful (87.3%). Quicker appointments, decreased travel cost and time, widely available free Internet with a good bandwidth enabling clear communication and test sampling at or near home may have contributed to client satisfaction.

It is estimated that there are over 500 million smartphone users (Indo-Asian News Service, 2020) and 525 million Internet users in India (India: Mobile Internet Users, 2020). The majority of Internet service providers offer unlimited free data. Most individuals referred to our center were able to successfully consult online, irrespective of socioeconomic status or geographical location. We selected ZOOM because it is a free web-based videoconferencing tool with over 300 million users in India (Chakravarti, 2020; UC & Riverside, 2020).

In the United States, health insurance covers the cost of genetic tests and consultation charges, whereas in India, these charges are self-paid by families. Payments for both teleconsultation and the cost of genetic tests were made through digital transaction portals (Unified Payment Interface and net banking). [UPI: 1.32 billion people use UPI portals in India] (Verma, 2020). This enabled seamless documentation and sharing of receipts between the clinic and the testing laboratories, both often located within the same institution.

4.1 | Advantages of teleconsultation

1. A shorter time interval between referral and an actual appointment was possible using teleconsultation. Patients were accommodated into the genetics clinics with lesser waiting time due to the reduced travel time of the genetics team to peripheral hospitals.
2. The majority of referred families reported satisfaction in being able to be seen in their home environment with their travel and clinical appointment time being reduced significantly.
3. Based on the clinical interactions with families, we speculate that a better level of communication was achieved as they were in the comfort of their own environment and not in a clinic setting.
4. Multiple family members, for example,. spouses stranded in different locations due to the travel restrictions during the pandemic, could also simultaneously participate virtually in a single consultation. Cascade screening of relatives could be done in some cases without arranging a separate appointment, especially in some autosomal recessive disorders where the joint family lived in a single home.
5. The clear images obtained due to good Internet bandwidth (5-10Mbps) allowed reasonably good phenotyping. The added advantage of seeing several members of a family in their own home allowed the comparison of dysmorphic with normal-appearing siblings.
6. A major advantage of teleconsultation was that trainees (doctors and counselors) could be virtual observers during the consultation and have discussions with the trainers after the clinic.In summary, quicker appointments, decreased travel (costs and time) to clinics, widely available free Internet with a good bandwidth (5 to 10 Mbps) enabling clear communication and test sampling at or near home may have contributed to client satisfaction.

4.2 | Some challenges

1. Teleconsultation at or around the home reduces privacy for the family member concerned. Because many families continue to live as joint families with numerous members in small homes, complete privacy may not be achieved during the consultation. Employing the services of a relative as a translator may further complicate confidentiality issues.

2. Inspite of overall satisfaction with the virtual consultation, around 74% indicated a preference for a face-to-face consultation. The reasons for this included a cultural perception of confidence when meeting a doctor in person and also because online consultation was a new experience for some individuals
3. In a few cases, despite sending instructions in advance of the clinic, family members did not download the ZOOM application or connect as per instructions on time. This caused delays lasting anywhere from 5 to 15 min at the beginning of the appointment.
4. Since clinic summaries and genetic test results are sent via public websites that are not usually encrypted, issues of confidentiality may arise.

4.3 | Special situations

Exclusive of the 539 patients, 30 more patients with lysosomal storage disorders (LSDs) receive weekly or fortnightly enzyme replacement therapy (ERT) at our center. Due to COVID-19-imposed travel restrictions, travel between districts was not possible for extended periods. Special permission and travel passes were obtained from authorities with the assistance of the Organization of Rare Diseases in India (ORDI), a patient support group. This enabled families to travel across district borders in sanitized private vehicles to and from the ERT center ensuring that none of the patients on rare disease therapy missed receiving timely doses highlighting the need for a good understanding between doctors, treating centers, patients' families, and support groups.

4.4 | Conclusion

To mitigate the difficulties faced by patients and families with genetic disorders to obtain in-person consultation during the ongoing COVID pandemic, we took advantage of the wide availability of Internet and telecommunication services in India to conduct online video clinics for 539 patient families with known or at risk of genetic disorders. The services provided included diagnosis based on clinical features, testing followed by genetic counseling, advice on management, and treatment. Both new and follow-up cases received a consultation with repeat appointments finding it easier to connect. While there were obvious advantages to the patient in obtaining telegenetic services, attention is also drawn to a few challenges that we encountered. We believe that telegenetics can be a viable alternative to in-person consultation even in the absence of an epidemic situation.

5 | THE STUDY INCLUDES ORIGINAL DATA

The authors Nivedita Rao and Meenakshi Bhat confirm that they had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. All of the authors gave final approval of this version to be published and agree to be accountable for the all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

AUTHOR CONTRIBUTIONS

N. Rao, D. Kanago, M. Morris, V. Narayan, K. Varshney, GN Sanjeeva, and M. Bhat made substantial contributions to the conception of the work, the acquisition, analysis, and interpretation of the data, assisted in drafting the initial manuscript and revisions, gave final approval of the version to be published, and agrees to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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COMPLIANCE WITH ETHICAL STANDARDS

CONFLICT OF INTEREST

N. Rao, D. Kanago, M. Morris, V. Narayan, K. Varshney, GN Sanjeeva, M. Bhat declare no conflicts of interest.

HUMAN STUDIES AND INFORMED CONSENT

This study was approved by and conducted to the ethical standards of the institutional ethics committee, Centre for Human Genetics, Bangalore. IRB number: CHG/077/2020-21/004. All applicable international, national and/or institutional guidelines were followed. This study was approved by the expedited review and was granted an informed consent waiver.

ANIMAL STUDIES

No non-human animal studies were carried out by the authors of this article.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request.

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