

SPECIAL ISSUE

Sudden shift to remote genetic counseling during the COVID-19 pandemic: Experiences of genetics professionals in Italy

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Abstract

The 2020 COVID-19 pandemic has rendered in-person provision of genetic counseling impossible for prolonged periods in many countries, mandating a sudden shift to remote delivery. We used qualitative thematic analysis to explore Italian genetics professionals' experience with remote genetic counseling. Fourteen group and four individual interviews were conducted after participants had delivered one or more remote sessions via videoconference or on the telephone. Data were coded and grouped under themes. Three main themes were identified as follows: (a) technical and logistical issues, (b) communication issues, and (c) clinical content and outcome of the session. The participants acknowledged that not having to travel to the clinic saves consultants time and expense. They also highlighted that not sharing a physical space with consultants and having to rely on technology can negatively impact on effective communication, building trusting relationships, and performing accurate psychosocial assessments. Regarding the clinical content of sessions, remote genetic counseling was perceived to favor greater focus and succinct, to the point communication. However, participants also felt uncomfortable not being able to use visual aids to support the explanation of complex concepts. Moreover, demographics and the socio-cultural status of consultants emerged as factors influencing the outcome of remote genetic counseling sessions. Finally, participants reported feeling that more experience with this novel approach would improve their confidence and their ability to adapt their counseling skills as appropriate. Based on these findings, we suggest that effective, equitable provision of remote genetic counseling will require an infrastructure that is able to support video counseling, sharing of clinical documents and visual aids, and connect with a wide range of devices. Moreover, the structure of sessions should be tailored to the specific requirements of remote genetic counseling and suitable training efforts should be promoted to enhance professionals' communication skills.

KEYWORDS

coronavirus disease 2019, COVID-19, pandemic, reflexive thematic analysis, remote genetic counseling, telemedicine, telephone genetic counseling

1 | INTRODUCTION

Remote genetic counseling is increasingly used as an alternative mode to provide genetic counseling. This growth has been spurred by a rise in demand for genetic care coupled with a shortage in medical genetics professionals (Cohen et al., 2012). Studies comparing in-person and remote genetic counseling have shown that consultands are equally satisfied (Jenkins et al., 2007; Schwartz et al., 2014), and that there are no differences in terms of knowledge acquired during the counseling (Jenkins et al., 2007; Schwartz et al., 2014), anxiety, well-being (Jenkins et al., 2007), or engagement in healthier behaviors (Helmes et al., 2006).

Although the US National Society of Genetic Counselors started to assess models for remote genetic counseling delivery as early as in 2009 (Cohen et al., 2012), little remains known about the views and experiences of genetics professionals who practice it. One study suggested that professionals perceive telephone genetic counseling as different from the traditional approach, finding it more difficult to establish a helping relationship through nonverbal communication and to explain biological and genetic concepts without visual aids (Burgess et al., 2016). Another study highlighted how characteristics of the consultand such as race/ethnicity can influence the effectiveness of telephone sessions as perceived by the counselor (Jacobs et al., 2016).

The COVID-19 pandemic has rendered in-person provision of genetic counseling impossible for prolonged periods in many countries, suddenly making remote delivery the only feasible approach (Mahon, 2020; Pagliuzzi et al., 2020). We present here a qualitative exploration of factors affecting the provision and outcome of remote genetic counseling during the pandemic, in order to prepare for successful implementation of remote genetic counseling in routine care in Italy.

2 | METHODS

2.1 | Study design

This study was conducted through interviews with genetic counseling providers. The interviews were unstructured, as the absence of any interview guide was felt to help take a vaster sweep of experiences. Interview data were then analyzed using reflexive thematic analysis (Braun & Clarke, 2006, 2019). Reflexive thematic analysis is not bound by methodological commitments, grants researchers the freedom to draw on the theoretical framework of their choosing to make sense of their data and is used to identify and describe both implicit and explicit ideas within the data, through extraction of themes. We considered it appropriate to examine the experience of genetic counseling providers through an inductive approach which privileges professionals' perspectives rather than through a pre-conceived analytical framework.

What is known about this topic

Studies have found that genetics professionals perceive that remote genetic counseling can make it more difficult to establish helping relationships with consultands, as it interferes with nonverbal communication, and to explain complex concepts, as it hinders the use of visual aids. To the best of our knowledge, no previous study has explored the views and perceptions of Italian genetics professionals regarding remote counseling.

What this paper adds to this topic

Professionals offering remote genetic counseling may be faced with a number of specific issues, particularly when they have little experience with it. In our view, overcoming the technical and logistical issues that may be associated with remote genetic counseling would not require large resources and is entirely feasible, as is the required improvement of professionals' communication skills.

2.2 | Participants

Genetics professionals were recruited among the clinical genetics staff belonging to the Medical Genetics Unit of the University Hospital S. Orsola-Malpighi in Bologna, Italy. Recruitment was conducted at staff meetings and participation was voluntary. All the genetics professionals belonging to the Medical Genetics Unit were eligible to take part in the study, including (a) clinical geneticists (CG), (b) clinical geneticists in training (CGT), and (c) genetic nurses (GN).

2.3 | Procedures

Group and individual interviews (abbreviated as GI and I, respectively) were conducted in a private room at the end of the working day and focused on the counseling sessions (one or more) delivered during that day. For sessions involving more than one professional, group interviews were preferred as they stimulate discussions and the sharing of views and experiences (Moser & Korstjens, 2018).

2.4 | Ethics

The study followed the principles of the Declaration of Helsinki and obtained ethics approval from the Ethics Committee of the University of Bologna on April 7th 2020 (approval number 171175). The participants gave their written informed consent after receiving both written and verbal information about the study, including the voluntary nature of participation, the possibility to withdraw at any time without

explanation and assurance that all collected data would be handled confidentially and no individual would be identifiable in quotes or in the results. Only the research team had access to the original interview files and transcripts.

2.5 | Setting

The Medical Genetics Unit at the University Hospital S. Orsola-Malpighi in Bologna provides genetic counseling and diagnosis for a wide range of genetic diseases. In a sample year (2019), 3,636 genetic consultations were performed: 1,247 postnatal, 753 for cancer and 481 prenatal counseling sessions. Genetic counseling is routinely offered in person, except sporadically, for example, when an urgent genetic test response is needed and the consultant is unable to reach the clinic; each genetic counseling session is provided by a clinical geneticist, and lasts 40–50 min on average.

At the end of March 2020, SARS-CoV-2 virus accounted for 105,789 infections and 12,401 deaths in Italy (World Health Organization, https://www.who.int/docs/default-source/coronavirus/situation-reports/20200331-sitrep-71-covid-19.pdf?sfvrsn=4360e92b_8), making our country one of the worst affected. In response to the COVID pandemic, starting on 13th March 2020 remote care services have been provided at the Hospital to outpatients, fully replacing in-person consultations. The Medical Genetics Unit thus began to engage in remote genetic counseling sessions.

2.6 | Genetic counseling protocol

Consultands scheduled for genetic consultation at our clinic were contacted to arrange a videoconference (using Skype) or a telephone call instead of an in-person session. The choice between videoconference and telephone call depended on the equipment available and the preference of professionals and consultands. Genetic counseling sessions were provided by a senior medical geneticist, who in most cases was joined by a CGT and sometimes also by a GN. Consultands were called either from the office where in-person genetic counseling usually takes place, or from the personal office of a physician, if properly equipped. The structure of genetic counseling sessions was in line with the standard of care. First consultations lasted approximately 40 min on average and included detailed family history collection, genetic risk assessment, discussion about the possible results and implications of future testing, if appropriate, and presentation of the options for risk management. Post-test counseling sessions included disclosure of test results, clinical interpretation, and management plans.

2.7 | Data collection

All interviews were performed between April and May 2020 and were facilitated by the same interviewer (LG), to ensure that the

participants would be subject to a constant interviewer effect. As interviews were unstructured by design, they began with a very general question like “What are your impressions about the remote genetic counseling sessions you delivered today?” Interviews were recorded and transcribed verbatim, with names and other identifying information altered to ensure confidentiality.

2.8 | Data analysis

Data were analyzed using reflexive thematic analysis. LG listened to the digital recordings and transcribed the interviews, then transcriptions were checked by BB, who also listened to the audio recordings. The six phases described by Braun and Clarke (Braun & Clarke, 2019) were followed in the data analysis. Phase one involved familiarizing with the data: both during and after the interviews, the interviewer took notes about impressions and possible interpretations. Once the data had been transcribed, all the interviews were read and reread by LG and BB. The data were then analyzed inductively and categorized using constant comparative methods. In phase two, more detailed and systematic work was carried out on the data to generate codes. Each transcript was explored using open thematic coding. In this process, we extracted the meaning content from the data, which were organized around similar codes and meanings. In phase three, themes were constructed, built and modeled across the data, based on the research questions and the researchers' interpretations. An overview of tentative themes and sub-themes was created based on the patterns and statements in the text. In this phase, some statements were categorized under more than one theme, as they were still perceived as overlapping and difficult to place. After the initial coding, sorting and thematizing, we agreed on the codes and themes that were necessary to proceed to the next analytical level. In phase four, all the themes were discussed and revised to avoid overlaps and to gain a clear sense of how each of those was related to the others, then they were checked across the whole data set. In phase five, the themes were defined and given more clarified names to convey the essence of the empirical data. The analytic work was wrapped up in the sixth phase, producing this article, which involved checking how well the themes worked, together and individually. Thematic analysis was performed on the transcribed interviews in Italian; themes, codes, and quotes were then translated from Italian into English.

2.9 | Rigor

Because it is subject to researcher bias, qualitative research is sometimes felt to lack scientific rigor, as well as reproducibility and generalizability (Mays & Pope, 1995). Here, rigor was optimized by employing robust qualitative research methods (Neergaard et al., 2009; Sandelowski, 2000; Sofaer, 1999), adhering to standards for qualitative research (Tong et al., 2007), and using rigor-enhancing

techniques (Barbour, 2001; Braun & Clarke, 2006) in the process of transcription, coding, analysis, and creation of the written report. Specifically, we ensured that the data had been transcribed with an appropriate level of detail by double-checking audio recordings; independent coding by two authors guaranteed that all data was considered equally, and re-analysis of the original data set after coding ensured that all coded items were collated and all themes checked (Braun & Clarke, 2006).

3 | RESULTS

Six geneticists, six geneticists in training, and one genetic nurse were prospectively enrolled in the study. Participant's ages ranged between 27 and 56 years. Years of clinical experience ranged between six and 30 years for CGs, between one and five for CGTs and was two years for the GN. Each participant conducted from three to 13 remote genetic counseling sessions (mean: five sessions) over the course of the study (Table 1).

A total of 18 interviews (14 group and four individual interviews) were conducted. Most participants were female (10, 76.9%). The length of interviews ranged between 25 and 45 min. Each participant was interviewed from one to seven times. Details on each interview are shown in Table 2.

As reported in Table 3, the codes that emerged from the analysis of the interviews were classified into sub-themes belonging to three main themes corresponding to the most relevant factors involved in remote genetic counseling, according to the participants:

(a) technical and logistical issues, (b) communication issues (c) clinical content and outcome of the session.

3.1 | Technical and logistical issues

Compared to in-person counseling, remote genetic counseling was found to have advantages and disadvantages.

Concerning the advantages, participants reported that remote genetic counseling facilitated a more flexible approach to organizing consultations; for instance, it allowed grouping together multiple relatives and/or professionals who would not have been able to participate in-person at the same time.

CG_5: Having the session now and being joined by my neuropsychiatrist colleague was definitely useful because it allowed her to plan the next steps right away.
(GI-12, video, pediatric genetic counseling)

Because it could be conducted from professionals' offices as well as from the dedicated room, remote genetic counseling also shortened wait times—which participants perceived could relieve consultands' worry and distress—and made offering consultands multiple sessions possible, if appropriate.

CGT_5: It cut wait times, and waiting would have increased their anxiety; learning about their shared familial risk was an unexpected thing, so having the chance

TABLE 1 Characteristics of genetics professionals recruited in the study

ID	Professional role	Years of experience	Number of video sessions provided	Number of telephone sessions provided
CG_1	Clinical geneticist	25	0	13
CG_2	Clinical geneticist	8	0	4
CG_3	Clinical geneticist	14	0	4
CG_4	Clinical geneticist	22	1	2
CG_5	Clinical geneticist	7	2	1
CG_6	Clinical geneticist	29	3	0
CGT_1	Clinical geneticist in training	1	0	9
CGT_2	Clinical geneticist in training	4	1	1
CGT_3	Clinical geneticist in training	3	4	2
CGT_4	Clinical geneticist in training	2	0	1
CGT_5	Clinical geneticist in training	4	1	0
CGT_6	Clinical geneticist in training	1	0	2
GN	Genetic Nurse	2	0	10

TABLE 2 Characteristics of individual and group interviews

ID	Type of genetic counseling	Number of sessions discussed during interview	Video/Telephone genetic counseling	Number of participants
GI-1	Cancer genetic counseling	1	Telephone	3 (CG_1, CGT_1, GN)
GI-2	Cancer genetic counseling	3	Telephone	3 (CG_1, CGT_1, GN)
I-3	Prenatal genetic counseling	1	Telephone	1 (CG_2)
GI-4	Cancer genetic counseling	3	Telephone	3 (CG_1, CGT_1, GN)
I-5	Prenatal genetic counseling	4	Telephone	1 (CG_3)
GI-6	Cancer genetic counseling	1	Telephone	3 (CG_1, CGT_1, GN)
I-7	Cancer genetic counseling	3	Telephone	1 (CG_1)
GI-8	Cancer genetic counseling	1	Telephone	3 (CG_1, CGT_2, GN)
GI-9	Adult genetic counseling	1	Telephone	2 (CG_4, CGT_3)
I-10	Prenatal genetic counseling	1	Telephone	1 (CG_2)
GI-11	Adult genetic counseling	1	Telephone	2 (CG_5, CGT_4)
GI-12	Pediatric genetic counseling	1	Video	2 (CG_5, CGT_2)
GI-13	Cancer genetic counseling	1	Telephone	3 (CG_1, CGT_1, GN)
GI-14	Pediatric genetic counseling	1	Video	2 (CG_5, CGT_5)
GI-15	Adult genetic counseling	3	Video	2 (CG_6, CGT_3)
GI-16	Adult genetic counseling	1	Video	2 (CG_4, CGT_3)
GI-17	Adult genetic counseling	1	Telephone	2 (CG_4, CGT_3)
GI-18	Prenatal genetic counseling	2	Telephone	2 (CG_2, CGT_6)

Abbreviations: CG, Clinical geneticist; CGT, Clinical geneticist in training; GI, Group Interview; GN, Genetic Nurse; I, Individual Interview.

to talk to this family after such a short time helped reassure them.

(GI-14, video, pediatric genetic counseling)

CG_2: Providing counseling on the phone meant that we were able to have a conversation even before the amniocentesis, which would not have been possible in routine care because the amniocentesis was being performed elsewhere.... It was two phone calls: one with the wife and one with the husband, they were apart and because we spoke with them on the phone, we were able to talk with both, which would not have usually been possible. So, yes, it was very helpful.

(I-10, telephone, prenatal genetic counseling)

Quick sessions could also be offered to consultands who requested a genetic assessment, but who had a low risk of having a genetic condition. This provided quick reassurance to consultands and freed up time for other appointments.

CG_4: It was just a matter of reassuring her and making sure she understood that she doesn't have an elevated risk and doesn't need any special tests or surveillance, which she was worried about, so it was good because she was relieved.

(GI-16, telephone, adult genetic counseling)

CG_5: Yes, we spoke with the parents and briefly saw the child, briefly because we could not examine her, but even just looking at her we were able to rule out the congenital form of the condition.

(GI-14, video, pediatric genetic counseling)

Participants reported thinking that consultands who lived far would appreciate not having to travel to the Hospital. Some participants also felt that this could reduce anxiety for some consultands.

CG_1: When we see them in person it can be more complicated because they need to find parking, some need to take time off from work, but this way they are comfortably at home and they can take advantage of not having to organize things, which worries them and makes them more anxious.

(GI-13, telephone, cancer genetic counseling)

However, some felt that staying at home and waiting for a phone call can also be stress-inducing:

CGT_1: There was one thing she said about anxiety "I was anxiously waiting for your phone call". So I wondered which makes people more anxious, waiting for the call at home or sitting in our waiting room and waiting to be called ...

TABLE 3 Results of the analysis

Initial codes	Sub-themes	Main themes
Grouping multiple relatives and/or professionals Reducing wait time Multiple sessions possible Quick conclusion of easy or not completely appropriate cases Reducing anxiety related to travel organization	Advantages/opportunities associated with technology and organization	Technical/logistical issues
Waiting for a scheduled phone call Problems with the technology Video-conference associated with artificial behavior Video-conference associated with frequent distractions	Disadvantages associated with technology and organization	
Nonverbal communication (video) Nonverbal communication (telephone) Meaning of silence Patient difficulties with trust Communication of relatives with consultant and/or genetics professional Focus on consultant Difficulties interpreting couple and family dynamics Lack of support by family members	Communication issues Trust in healthcare professionals Family dynamics	Emotions/communication
Increased length of assessment More focused on the topic Conciseness Less time/less opportunity to manage all the information Patients' background Patients' lack of familiarity with technology Lack of visual cues Inability to conduct a physical exam	Focus/Preparation/Evaluation Reliance on consultant's technical skills	Content and outcome of the session (medical)

CG_1: Because actually, having to wait at home, doing nothing, it's a strange situation ... (usually) you know you need to go and you need to organize things, which distracts you from being anxious about the session itself.
(G1-2, telephone, cancer genetic counseling)

On the other hand, technical issues interfering with communication were seen by many as a major disadvantage of remote genetic counseling, whether on the phone or via video-conference.

GN: I had trouble catching words. I often couldn't understand what she was saying and tried to infer (it from context). I was often concentrated on listening rather than on what she was saying. It was definitely a technical problem, we were both using speakerphones.
(G1-1, telephone, cancer genetic counseling)

CG_1: The first post-test session didn't go very well, I couldn't hear, I don't know if the problem was on my end. So it went poorly because of a technical problem.
(G1-7, telephone, cancer genetic counseling)

CG_5: I think it went well, the only problem was with the quality of the videocall, I think because of where they were. [...] Aside from the problems with audio quality.
(G1-14, video, pediatric genetic counseling)

Participants also reported that videoconferences could make people behave "unnaturally" (moving less, speaking differently), be negatively affected by sound and/or image delays, and cause frequent distractions:

CG_2: She is sitting completely still because she has to be visible for the camera, she is not behaving naturally and nor are you, you are concentrated on being visible and on speaking louder because you're not sure whether your voice comes across clearly ... We are all used to using the phone with no video, the video embarrasses you, being filmed doesn't make you behave more naturally, I find it really artificial. No, you can't concentrate on the person, everything is delayed.

(GI-18, telephone, prenatal genetic counseling)

3.2 | Communication issues

Participants highlighted the negative impact of remote genetic counseling on nonverbal communication. Lack of eye contact and not being able to see consultands' posture, facial expressions, body positioning, or accurately hear voice quality, tone and hesitations, all of which can be important in assessing emotions, was associated with difficulties in providing emotional support and unease in discussing sensitive issues. Regardless of whether counseling was delivered on the phone or via teleconference, participants complained about their perceived inability to provide physical gestures of support and express empathy.

CG_4: I felt a bit uncomfortable, not being able to see them, I missed the visual, physical, human presence ... [...]

CGT_3: And maybe giving bad news on the phone, emotionally you are more removed, the empathic connection is easier for them to feel when you are physically present.

(GI-9, telephone, adult genetic counseling)

CG_3: When something comes up, being able to see each other helps, it helps you understand whether the patient is following you, if they understand ... So clearly the phone creates more problems in establishing an empathic connection, which of course you can do more easily when you meet in person, just by looking at her you understand what she hasn't understood, where you lost her.

(I-5, telephone, prenatal genetic counseling)

CG_1: I would have preferred to see the reaction, beyond what I heard on the phone, I would have been able to understand what this information meant to him.

(GI-4, telephone, cancer genetic counseling)

Compared to telephone calls, however, videoconference sessions were reported to be preferable in terms of nonverbal communication.

CGT_3: you have the visual contact and you can see how people react to what you are saying so there is an exchange.,

CG_6: If you see them, if you see their expression, it helps you understand whether they are following you or not.

(GI-15, video, pediatric genetic counseling)

During telephone calls, trouble understanding what silence meant was frequently reported.

CG_4: So I found myself having to explain this thing on the phone and on the other end there was silence, a rather deep silence on the other side.

(GI-9, telephone, adult genetic counseling)

GN: The silence made me uneasy: you talk and on the other end there is total silence. I wondered whether they were listening to me. Having no feedback gave me the feeling there was a void on the other end. [...] You can lose the connection on the phone; you might lose it and not realize it.

(GI-2, telephone, cancer genetic counseling)

The sense of uncertainty associated with silence seemed to be absent during videoconferences

CG_6: On Skype you can tell if you lose the connection, so you stop and contact them again. You see the reaction. [...] You are aware of talking to someone who is always there and listening to you.

(GI-15, video, pediatric genetic counseling)

Participants also reported that telephone counseling often helped keep the focus on the consultands, which they considered to be positive for shier, less confident individuals with intrusive relatives.

GN: The son would have probably been eclipsed by the father like other times, but instead, because he answered the phone and stayed on the phone... CG_1: He took on a more active role than other times.

(GI-4, telephone, cancer genetic counseling)

Conversely, telephone counseling was seen as translating into a lack of emotional and decisional support from relatives, as well as in missed benefits for relatives who could have participated had the session been in person.

GN: She really gave the impression that she was leaning on her husband, so if she had come here, she would have probably looked to him to make a decision ... Many

women do, they look at the man with them and ask him what to do, so since she felt she was on her own having to give an answer about an appointment and take the responsibility of fixing a date without asking anyone else.

(GI-6, telephone, cancer genetic counseling)

CG_1: ...In person she would have come with her mother so the benefits would have been shared with her mother, who would have been reassured about not having passed on her susceptibility to her daughter ... (It was a problem) not having much of a chance to communicate (because of the telephone) with someone who is feeling anxious, maybe clinically so, and the fact that there is no one there with her, who in this case would have been her mother [...]

(I-7, telephone, cancer genetic counseling)

Remote counseling, especially on the phone, was also associated with difficulties recognizing who was talking and interpreting couple and family dynamics.

CG_1: She told us he (her son) was there on speaker-phone, but he never spoke so we don't know whether he was worried, so ... She asked a few specific questions about implications for her son only at the end. [...] I do expect that they had a conversation once they put the phone down. When we meet in person this happens during the session, they have a conversation, one shares a concern, the other answers with their thoughts and clarifies things. (In person) the other people present participate more, here it mostly is a conversation between the consultand and the professional with no great participation from the other people there.

(GI-1, telephone, cancer genetic counseling)

CG_4: Well you know, on the phone, it was difficult to understand who was talking, whether it was the father or the son...

(GI-9, telephone, adult genetic counseling)

CG_3: When a couple comes to the clinic ... you observe the dynamics within the couple and how each one perceives what is being discussed during the first five minutes of the session. So seeing them, how they sit down, how they talk with each other, how they talk to you, who answers, it helps you understand how they relate to one another and because you are talking about very important things, things they about which they are going to be making decisions and may not agree ...

(I-5, telephone, prenatal genetic counseling)

Participants perceived that, having only met them remotely, consultands could find it difficult to trust them.

CG_3: You really need to establish a trusting relationship It is harder in prenatal counseling and in medical genetics if you have a person who is affected by a condition and is being given a diagnosis, that diagnosis may change their life, it's the same thing in presymptomatic individuals ...

(I-5, telephone, prenatal genetic counseling)

CG_1: ... (what is missing is) the feeling of being reassured by coming to the clinic, in a hospital with a sign and staff wearing white coats..., the phone call has none of all of this context. You get a phone call from people who are completely unknown to you.

(GI-6, telephone, cancer genetic counseling)

CG_1: [...] Not being physically here made her a little more mistrusting, so at the end she asked me to repeat my name, being physically present might be reassuring for these people.

(GI-8, telephone, cancer genetic counseling)

CG_2: [...] Specifically the husband needed to imagine who I was so he asked questions that people never ask in person, like how old I was.

(I-10, telephone, prenatal genetic counseling)

This problem was minimized by the use of video-calls:

CGT_2: (On Skype) They would see you wearing your white coat and you see them, at least we see one another and certain things are easier [...] being able to see each other, even remotely, is definitely a plus.

(GI-8, telephone, cancer genetic counseling)

CGT_3: Being able to see each other helps establish a relationship with the patient. I thought it wasn't bad at all, we established good rapport.

(GI-15, video, pediatric genetic counseling)

3.3 | Clinical content and outcome of the session

Compared with in-person sessions, remote genetic counseling sessions were perceived as more focused, to-the-point and succinct.

CG_6: In person you sometimes go off-topic and they ask you about other things, with this kind of

counseling we focus on the problem right away so it's well focused on the main issue

CGT_3: Yes it's true, I've noticed that too, because you need to understand how things went because you don't have any other information (about the history of the patient/family).

(GI-15, video, pediatric genetic counseling)

However, while consultands usually take their (and sometimes their relatives') medical files with them to in-person sessions at the clinic, giving geneticists the opportunity to review the files before the appointment, this is not the case with remote genetic counseling. Participants reported that files available to them before remote genetic counseling sessions were often either lacking or incomplete. Some participants therefore felt they were not sufficiently prepared to meet consultands' needs.

CG_4: ... I felt uneasy, talking about this without knowing ... I was planning to call them to suggest some tests, instead ... I was totally unprepared.

(GI-9, telephone, adult genetic counseling)

CGT_6: Having no documentation at that time (of the session), which I went over later, ... was the problem

CG_6: It would be taken in a single session (had the documentation available earlier)

(GI-18, telephone, prenatal genetic counseling)

Participants also reported feeling uncomfortable because of the lack of visual aids (when talking on the phone or when the video chat did not allow using them) to help explain complex information as well as the impossibility of performing a physical exam.

CG_1: In person you have the opportunity to go over things together. For instance, you read

the report over with the patient. And that can prompt them to ask questions, more than if they are just listening to you.

(GI-4, telephone, cancer genetic counseling)

CG_4: ... even a little drawing could help explain this.

(GI-9, telephone, adult genetic counseling)

CG_6: (in that situation) there was no physical examination. When the diagnosis is uncertain (it is crucial) When the diagnosis is certain, seeing (the patient) is always

better but since you have the genetic information you can make the assessment.

(GI-15, video, pediatric genetic counseling)

Trouble making an assessment of how much consultands understand was also reported.

CG_1: On the phone there are fewer opportunities to go back on ideas and get feedback. This is what leaves me a bit dissatisfied with not having had the session in person.

(GI-4, telephone, cancer genetic counseling)

With experience, however, some participants began to feel more confident:

CG_6: I think the session today went well, it's one of the best so far

CGT_3: Yes, I agree, we must be getting better at it.

(GI-15, video, pediatric genetic counseling)

CG_3: (Unlike when I had just started remote consultations, now) on the phone I often ask the consultand if they want to recap the main topics of our conversation so I can check and see when they tell me which points did not come across at all and what their perception is because clearly not seeing me the perception isn't always right.

(I-5, telephone, prenatal genetic counseling)

According to the participants, consultands' personal characteristics, such as their age, education level, awareness of family history and disease, and level of comfort with the technology used for remote genetic counseling, strongly influenced the outcome of counseling, either as facilitators or as barriers.

CG_6: [...] (in this case) it was two educated people who were very capable with technology

CGT_3: [...] (in the other case) it was difficult, they were less well-educated and their knowledge was more basic.

(GI-15, video, pediatric genetic counseling)

CG_6: She was a young, bright, 27 year-old woman, I don't think there was any trouble; maybe in other situations it would have been better to be able to see each other, but we had no trouble at all with her [...] it really depends on the other person (consultand).

(GI-17, telephone, adult genetic counseling)

CG_4: I think so, certainly in person we could draw something to explain dominance and recessive patterns of inheritance

CGT_3: ...but she understood it all the same, she used specific terms like homozygosity and heterozygosity, she seemed to understand what she was talking about.
(GI-16, telephone, adult genetic counseling)

The possibility to deliver counseling via videoconference rather than on the phone was also determined by what kind of tools were available to consultands and whether they were able to use them:

GS: The session was mostly on the phone because the mother couldn't use Skype, she didn't have it.
(GI-11, telephone, adult genetic counseling)

4 | DISCUSSION

The aim of this study was to investigate the experience of Italian genetics professionals with remote genetic counseling after the 2020 COVID-19 pandemic mandated a sudden shift to remote care, to which they were largely unprepared (Omboni, 2020). Our results, obtained through reflexive thematic analysis of 18 interviews with 13 professionals providing remote genetic counseling, show that major issues perceived to influence remote genetic counseling provision and outcome belonged to three main themes: (a) technical and logistical issues, (b) communication issues, and (c) clinical content and outcome of the session. The main themes are determinants that can significantly affect the provision and outcome of remote genetic counseling and that need to be taken into account in order to prepare for successful implementation of remote genetic counseling in routine care in Italy.

Technical issues (poor quality connections, visual, or audio problems) were perceived as largely influencing the quality of the interaction with consultands. Other authors have also described technical issues as a main complaint and a major cause of dissatisfaction with remote genetic counseling (Lea et al., 2005; Meropol et al., 2011; Otten et al., 2016; Pestoff et al., 2019). Subsequently, several studies assessing the outcomes of remote genetic counseling included prior assessment of the technology available to the patients and provision of instructions on how to download and use IT platforms (D'Agincourt-Canning et al., 2008; Meropol et al., 2011; Otten et al., 2016).

According to our participants, not having to travel to the clinic saved consultands' time, money, and worry, which was a clear advantage compared to in-person consultations. A number of other studies have also showed that consultands' positive attitudes toward remote genetic counseling are mainly related to shorter travel time, shorter waiting time at the clinic, reduced costs associated with travel and parking and fewer difficulties obtaining time off work (Abrams &

Geier, 2006; Buchanan et al., 2015; Coelho et al., 2005; D'Agincourt-Canning et al., 2008; Lea et al., 2005; Orlando et al., 2019; Pestoff et al., 2019; Zilliacus et al., 2009). In addition, it has been suggested that remote genetic counseling may help consultands who experience social or hospital anxiety feel more at ease (Zierhut et al., 2018).

In previous studies, clinicians' experience with remote genetic counseling has been generally found to be positive, with many reporting it can be a good alternative to face-to-face consultations in certain clinical scenarios (Downes et al., 2017). In our study, instead, participants reported both positive and negative feelings about it, possibly owing to the novelty of this practice for the professionals we interviewed. Indeed, a subset reported feeling more confident and satisfied with the new counseling approach once they had acquired some experience.

Our participants also pointed to the limitations in nonverbal communication inherent to remote genetic counseling, which they felt interfered with their ability to perform accurate psychosocial assessments. As described previously by Bradbury et al. (Bradbury et al., 2011) and Burgess et al. (Burgess et al., 2016), our participants felt that the inability to read consultands' facial expressions and body language adversely impacted their ability to pick up their emotional responses and build rapport.

Interestingly, studies reporting consultands' perceptions and views have generally found equivalent satisfaction between remote genetic counseling and in person genetic counseling (Baumanis et al., 2009; D'Agincourt-Canning et al., 2008; Platten et al., 2012; Schwartz et al., 2014) and a large percentage of participants to one study reported they would not have undergone genetic counseling had they not had the option of telephone sessions (Sutphen et al., 2010). Overall, consultands are thought to be more satisfied with genetic counseling when they are allowed to choose the mode of delivery (Baumanis et al., 2009).

According to our participants, remote genetic counseling is more focused on the individual consultand and on the specific condition. While focusing specifically on the consultand may support autonomous decision-making when there is a risk of interference from relatives (Battistuzzi et al., 2019), as in the case of young adults experiencing pressure from parents to have genetic testing (Godino et al., 2016, 2018, 2019), strictly focusing on the condition and spending less time with the consultand may negatively impact on establishing rapport and thus hamper the outcomes of the session.

Along the same lines, and again consistently with the findings of Bradbury et al. (2011) and Burgess et al. (2016), several participants felt that not being able to use visual aids when counseling on the phone interfered with communication. Burgess and colleagues, however, have suggested that not being able to use visual aids in telephone genetic counseling is an issue for professionals but not necessarily for consultands (Burgess et al., 2016). The discomfort experienced by professionals not using the usual communication strategies may thus not necessarily be associated with true consultand misunderstanding.

Common concerns emerging from our interviews were the difficulty to assess a consultand's understanding by telephone, due to

the inability to see nonverbal cues suggesting the consultand is confused or does not understand, and the difficulty to understand the meaning of silence.

Although silence is a natural part of every conversation, representing either a pause during speech, or simply “thinking time” (Chatwin et al., 2018), silence during a telephone call can be difficult to interpret and may suggest that the consultand is not able to follow the conversation, either because they don't understand what was said or because of a technical issue. Others have also found that consultand misunderstanding was noted by genetic counselors as a disadvantage of remote genetic counseling (Bradbury et al., 2011; Burgess et al., 2016). According to our participants, these issues may be solved by the use of videoconferencing. Not all consultands, however, will have access to video-based platforms or will be able to use them. Indeed, our participants pointed out that age and education may influence the ability to use videoconferencing platforms. Other authors have also reported that lack of technical capability was associated with socioeconomic disadvantage and older age, and suggested that efforts should be made to provide technical support and instruction, if necessary, to consultands who are less technologically savvy, ahead of the counseling session (Lally et al., 2020).

Beyond technical issues, a question raised by our findings is whether professionals providing remote genetic counseling should develop specific skills. This is supported by studies showing that, although remote genetic counseling and in person sessions mostly require the same skills, genetic counselors need to be taught additional skills or how to use their existing skills differently to provide effective remote genetic counseling (Derkx et al., 2009; Vaona et al., 2017). For instance, training in psychosocial assessment skills could include asking more direct questions and identifying different nonverbal consultand cues (such as inflection, pauses or sighing) to determine a consultand's emotional status (Derkx et al., 2009; Vaona et al., 2017).

Conversely, a lack of training in remote consultations might lead to large variation in professionals' behaviors over the telephone (Derkx et al., 2009; Vaona et al., 2017) with a negative impact on the standard of care provided. As genetic counseling is considered a “complex intervention” (Hooker et al., 2017; p.356), guidance on how remote sessions might be conducted, and what information should be obtained and provided, should be well defined; particularly, carefully structuring telephone consultations could improve the quality of the activity for both consultands and genetics professionals (Coffey & Begley, 2020).

4.1 | Study strengths and limitations

This study has several strengths. To the best of our knowledge, it is the first qualitative study that explores the experience of genetics professionals with remote genetic counseling in Italy. We employed robust qualitative research methods (Neergaard et al., 2009; Sandelowski, 2000; Sofaer, 1999) adhered to standards for

qualitative research (Tong et al., 2007) and used techniques to optimize rigor (Barbour, 2001; Braun & Clarke, 2006). We guaranteed that the data had been transcribed verbatim by double-checking audio recordings; independent coding by two authors ensured that all data was considered equally, and re-analysis of the original data set after coding ensured that all coded items were collated and all themes checked. We also recruited participants with a range of clinical expertise in the genetics clinic (cancer, pediatric, adult, prenatal) to enhance the reliability and validity of the findings. Moreover, the research team included experts with different backgrounds, which promoted a multidisciplinary approach to data understanding and interpretation.

A few limitations may influence the interpretation and application of these findings. First, all participants were recruited from the same clinic, located in Northern Italy; thus, the findings may not be transferrable to other settings or socio-cultural environments. Second, the findings are only based on providers' perceptions; the lack of information on the perceptions of consultands means that only a partial exploration of the issues at hand is provided.

4.2 | Practice implications

Remote genetic counseling may represent an important advancement in consultand care. By exploring the issues related to remote genetic counseling, as experienced by the genetics professionals who participated in this study, we hope to contribute to identifying the requirements and the needs of genetics clinics and professionals in this direction. First, effective provision of remote genetic counseling will require an infrastructure that is able to support video counseling, sharing of clinical documents and, possibly, visual aids. Genetics services offering remote genetic counseling should take into account that differences in access to and experience with technology may amplify existing health care equity issues associated with demographics and socioeconomic status. To overcome the digital divide and reach socially disadvantaged consultands, IT platforms should be used that can connect with a wide range of devices, and the connection should be checked prior the session. Moreover, the structure of sessions could be tailored to the specificities of remote genetic counseling by, for example, (a) obtaining clinical and family information before the session, (b) spending more time on introductions to promote building rapport and trusting relationships, (c) asking specific, pre-defined questions to elicit feedback from consultands to assess their understanding. Finally, in order to support professionals' confidence with this new approach and their ability to provide effective counseling, education efforts should be promoted to enhance communication skills and teach strategies useful for remote counseling.

4.3 | Research recommendations

Our qualitative study provides insights on the experience with remote genetic counseling of a limited number of professionals. To

confirm our findings, future research should explore a more comprehensive population of providers, ideally using a quantitative approach. Objective assessment of the outcome of remote versus in-person genetic counseling will require randomized trials and the use of validated questionnaires.

5 | CONCLUSION

Our findings, together with evidence from previous studies, highlight that healthcare professionals offering remote genetic counseling may be faced with a number of specific issues, particularly when they have little experience with it. However, this novel approach offers advantages to both consultands and genetics clinics that deserve to be pursued. In our view, overcoming the technical and organizational issues that emerged here would not require large resources and is entirely feasible, as is the improvement of professionals' communication skills through suitable training. These efforts will ensure that remote genetic counseling follows standardized guidance and is equally effective as in-person counseling in benefiting consultands receiving these services. Remote genetic counseling could be particularly advantageous in situations where consultands have difficulty reaching the clinic or when remote delivery is not expected to affect the outcome of the counseling session, as in the case of pre-test counseling in low-risk scenarios (e.g., genetic screenings) and post-test counseling for individuals with a non-informative test result and non-suggestive family history.

AUTHOR CONTRIBUTIONS

LG and DT coordinated the activities, performed thematic analysis, interpreted the results, and drafted the manuscript. LG facilitated the interviews. BB and LG transcribed the interviews and double-checked audio recordings for accuracy. LB provided bioethics support, contributed to the interpretation of the results and—as a native speaker of English—revised the manuscript for language. All the authors contributed to the manuscript, read and approved the final version of the paper.

ACKNOWLEDGEMENTS

We would like to thank all our colleagues who accepted to participate for their fruitful contribution to the study.

COMPLIANCE WITH ETHICAL STANDARDS

CONFLICT OF INTEREST

The authors Daniela Turchetti, Linda Battistuzzi, Benedetta Bertonazzi and Lea Godino declare that they have no conflict of interest.

HUMAN STUDIES AND INFORMED CONSENT

The study protocol conforms to the ethical guidelines of the WMA Declaration of Helsinki and was approved by the Bioethics

Committee of the University of Bologna, Italy (Protocol number 171175). All participants were informed about the purpose and the methods of the study via a participant information sheet. They were informed that they were free to decide to participate or not and they did not have to give a reason if they declined.

ANIMAL STUDIES

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

DATA SHARING AND DATA AVAILABILITY

The transcript interviews generated during and/or analyzed during the current study are available from the corresponding author on reasonable request.

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How to cite this article: Turchetti D, Battistuzzi L, Bertonazzi B, Godino L. Sudden shift to remote genetic counseling during the COVID-19 pandemic: Experiences of genetics professionals in Italy. *J Genet Couns*. 2021;30:1024–1037. <https://doi.org/10.1002/jgc4.1441>