

# The Role of Genetic Counseling in Patient Decision-Making: A Qualitative Study on Insights from Patients with Genetic Disorders

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## Abstract

**Background:** Genetic counseling plays a critical role in helping patients with genetic disorders make informed decisions about their health, treatment, and family planning. This study explores how genetic counseling shapes patient decision-making and addresses the emotional and psychological responses to genetic information.

**Methods:** A qualitative study was conducted at a tertiary hospital, where in-depth interviews were performed with 20 patients who had received genetic counseling. Thematic analysis was used to identify key themes related to information comprehension, emotional support, and decision-making confidence.

**Results:** Four key themes emerged: (1) Information as Empowerment, (2) Emotional and Psychological Support, (3) Decision-Making Confidence and Clarity, and (4) Uncertainty and Emotional Conflict. While most patients felt empowered and clearer in their decision-making after counseling, some experienced ongoing emotional conflict and uncertainty, particularly when dealing with ambiguous genetic results.

**Conclusion:** Genetic counseling significantly supports patients by providing both medical information and emotional care, but continued emotional support is necessary, especially for those facing uncertain outcomes. Genetic counselors should consider offering follow-up resources to help patients cope with the emotional weight of their decisions.

**Keywords:** Genetic counseling, patient decision-making, genetic disorders, emotional support, qualitative study, healthcare decisions

## Introduction

Genetic counseling has become an integral part of healthcare for individuals and families facing genetic disorders. It provides patients with critical information about their genetic conditions, helps them understand their risk factors, and supports them in making informed decisions about their health and future. Genetic counseling not only focuses on the transmission of medical information but also addresses the psychological and emotional aspects of dealing with a genetic disorder. Given the complex nature of genetic conditions, patients often face difficult decisions regarding diagnosis, treatment options, family planning, and lifestyle adjustments (Ramos, 2020).

The decision-making process for patients undergoing genetic counseling is multifaceted. Patients must navigate the implications of genetic risks for both themselves and their families, which can involve

considerations about preventive measures, treatment choices, and reproductive options. Genetic counselors are uniquely positioned to guide patients through these decisions by offering personalized information and emotional support (Smerecnik et al., 2019). However, the extent to which genetic counseling influences patient decisions and their emotional well-being remains an area of ongoing research.

Previous studies have highlighted the value of genetic counseling in empowering patients to make informed decisions. For instance, Douma et al. (2010) found that patients who receive comprehensive counseling are more likely to feel confident in their decision-making, particularly when it comes to complex issues such as prenatal testing or managing hereditary cancer risks. Despite these benefits, some patients still report feelings of uncertainty and anxiety after counseling, suggesting that additional emotional or psychological support may be needed (Aspinwall et al., 2013).

This study aims to explore how genetic counseling shapes the decision-making process for patients with genetic disorders. By focusing on patient experiences, this qualitative study seeks to understand how counseling impacts not only the choices patients make but also their emotional responses to those decisions. This research will provide insights into the effectiveness of genetic counseling in addressing both the cognitive and emotional aspects of decision-making in a highly sensitive context.

#### Research Objectives:

- To explore patient experiences with genetic counseling.
- To investigate the factors within genetic counseling that influence patient decisions.
- To examine the emotional and psychological impact of genetic counseling on patients with genetic disorders.

## Literature Review

### 1. Overview of Genetic Counseling

Genetic counseling has been recognized as a critical service that integrates medical, psychological, and familial aspects to help individuals understand and adapt to the implications of genetic disorders. Its role in healthcare is not only to provide patients with medical information but also to offer support in the emotional and psychological adjustment to a potential or confirmed diagnosis (Abacan et al., 2019). Genetic counselors act as mediators who help patients comprehend genetic risks, make informed healthcare decisions, and navigate the complex emotional responses associated with genetic conditions (Ramos, 2020).

A key component of genetic counseling is the personalization of information to match the patient's understanding and psychological state. The counselors must balance providing detailed, sometimes overwhelming, information while being mindful of the patient's emotional needs (MacLeod et al., 2021). By fostering a non-directive counseling approach, genetic counselors encourage patients to make autonomous decisions about their health and family planning without feeling pressured (Douma et al., 2010). However, the effectiveness of this approach in helping patients make informed and confident decisions has become a subject of increasing interest in recent studies.

### 2. Patient Decision-Making in Genetic Disorders

Decision-making in the context of genetic disorders is complex, involving medical, ethical, and emotional considerations. Patients are often required to make difficult choices about screening, treatment, reproductive planning, and lifestyle modifications after receiving genetic information (Smerecnik et al., 2019). Research

has shown that genetic counseling plays a pivotal role in guiding patients through this process by providing accurate information and emotional support.

A study by Douma et al. (2010) highlighted that patients receiving genetic counseling felt more empowered to make informed decisions, particularly in cases involving hereditary cancer risk or prenatal genetic testing. The study found that patients valued the clarity and structure provided by counseling sessions, which helped them weigh the risks and benefits of various medical options. However, the emotional toll of genetic information can sometimes overwhelm patients, making decision-making more challenging than anticipated (Aspinwall et al., 2013).

### 3. The Emotional and Psychological Impact of Genetic Counseling

The emotional and psychological impact of genetic counseling has been a critical focus in research, as patients often experience significant stress and anxiety when dealing with genetic conditions. Studies have consistently demonstrated that patients frequently struggle with the emotional implications of genetic diagnoses, including fear of disease progression, concerns about transmitting the condition to offspring, and anxiety about future health outcomes (MacLeod et al., 2021).

Smerecnik et al. (2019) found that genetic counseling often provides emotional relief to patients by helping them feel more in control of their situation. Counselors not only offer technical and medical expertise but also serve as emotional support figures. This dual role can help mitigate feelings of helplessness and isolation that often accompany genetic diagnoses. Nevertheless, there is evidence that some patients leave counseling sessions feeling uncertain or conflicted, particularly when confronted with ambiguous or uncertain genetic results (Aspinwall et al., 2013).

### 4. The Role of Genetic Counseling in Family Planning Decisions

Genetic counseling is particularly important in shaping family planning decisions for individuals and families with genetic disorders. Studies show that genetic counseling helps patients and families understand the potential risks of transmitting genetic disorders to their offspring, enabling them to make more informed reproductive decisions (Ramos, 2020). Counseling in this context involves discussing options such as prenatal testing, preimplantation genetic diagnosis (PGD), and the use of donor gametes, which can present ethical and emotional challenges for patients.

A qualitative study by Douma et al. (2010) explored the impact of genetic counseling on family planning decisions and found that many patients viewed the counselor as a critical resource in their decision-making process. The patients appreciated the counselor's ability to present complex genetic information in a way that was easy to understand, and they valued the emotional support provided during discussions about reproductive risks and options. However, the study also noted that some patients felt that the non-directive nature of genetic counseling left them feeling uncertain about the "right" choice to make.

### 5. Challenges in Genetic Counseling and Patient Decision-Making

Despite the overall positive impact of genetic counseling, several challenges persist in how patients navigate the decision-making process after counseling sessions. A systematic review by Smerecnik et al. (2019) revealed that patients with lower health literacy or those who are emotionally distressed may struggle to fully comprehend the genetic information provided during counseling. This gap in understanding can hinder effective decision-making and may lead to patient dissatisfaction.

Moreover, the non-directive nature of genetic counseling, while meant to empower patients, can sometimes create additional stress for individuals who are seeking more definitive guidance. Patients often report feeling overwhelmed by the responsibility of making decisions that could have profound consequences for their health and families (Aspinwall et al., 2013). Balancing the provision of information with the emotional well-being of the patient remains a challenge for genetic counselors.

## 6. Gaps in the Literature

While significant progress has been made in understanding the role of genetic counseling in patient decision-making, there are still gaps in the literature. For instance, few studies have thoroughly explored the long-term impact of genetic counseling on patient outcomes, particularly in the context of chronic conditions or ongoing decision-making related to genetic risks. Furthermore, there is limited research on how cultural, social, and economic factors influence the effectiveness of genetic counseling in diverse populations (Douma et al., 2010).

In addition, most studies have focused on the immediate effects of genetic counseling, leaving a gap in understanding how patients process genetic information and make decisions over time. The emotional and psychological long-term impacts of receiving a genetic diagnosis are also underexplored, especially in terms of how patients cope with the ongoing implications of their condition for themselves and their families (MacLeod et al., 2021).

## Conclusion

The literature demonstrates that genetic counseling plays a vital role in guiding patient decision-making, offering both informational and emotional support. However, the process remains complex, and challenges such as emotional distress, uncertainty, and health literacy can impact the effectiveness of counseling. By further exploring patient experiences, this study aims to address these gaps and contribute to a deeper understanding of the role of genetic counseling in shaping decisions for individuals with genetic disorders.

## Methodology

### 1. Study Design

This study employed a qualitative research design using semi-structured, in-depth interviews to explore the experiences of patients who underwent genetic counseling at a tertiary hospital. The qualitative approach was chosen to gain rich, detailed insights into how genetic counseling influenced patient decision-making, focusing on both cognitive and emotional responses to the counseling process.

### 2. Study Setting

The research was conducted at a tertiary care facility with a specialized genetic counseling unit. This hospital caters to patients diagnosed with a range of genetic disorders, including hereditary cancers, congenital conditions, and rare genetic diseases. The genetic counseling unit offers comprehensive services, including risk assessment, diagnostic testing, and decision support for patients and their families.

### 3. Participants

The participants of the study were patients who had received genetic counseling at the tertiary hospital. A purposive sampling method was used to recruit individuals who were diagnosed with a genetic disorder and had engaged in genetic counseling sessions during this period.

**Inclusion Criteria:**

- Patients aged 18 years or older.
- Patients who received at least one genetic counseling session.
- Patients diagnosed with a genetic disorder, including hereditary cancers, congenital conditions, or rare genetic diseases.
- Ability to provide informed consent and participate in a semi-structured interview.

**Exclusion Criteria:**

- Patients with cognitive impairments that might hinder their ability to provide informed consent or participate in the interview process.
- Patients who did not complete their genetic counseling session.

A total of 20 participants were included in the study, with an effort made to ensure diversity in terms of age, gender, diagnosis, and socioeconomic background.

**4. Data Collection**

Data were collected through in-depth, semi-structured interviews conducted. The interviews were carried out by the primary researcher in a private consultation room within the hospital to ensure confidentiality and comfort for the participants. Each interview lasted approximately 45 to 60 minutes.

An interview guide was developed to ensure that key areas were covered while allowing flexibility for participants to share their experiences in their own words. The guide included open-ended questions exploring the following areas:

- Participants' experiences during genetic counseling sessions.
- The role of genetic counseling in shaping decisions regarding treatment, family planning, and lifestyle.
- Emotional and psychological responses to the counseling process.
- Challenges faced in making decisions after counseling.

**Sample questions from the interview guide included:**

- "How did the genetic counseling session influence your decision-making about your health or family planning?"
- "Can you describe how you felt emotionally after receiving information about your genetic condition?"
- "What aspects of genetic counseling were most helpful in guiding your decisions?"

All interviews were audio-recorded with participants' consent and later transcribed verbatim for analysis.

**5. Data Analysis**

Data analysis followed the thematic analysis approach as outlined by Braun and Clarke (2006). The transcribed interviews were read multiple times to familiarize the researchers with the data. Initial coding was conducted to identify recurring patterns and significant statements related to patient decision-making and emotional responses.

From this coding process, broader themes were identified, including:

- The informational role of genetic counseling.
- Emotional support and psychological impact.
- Decision-making confidence and clarity.

- Uncertainty and emotional conflict post-counseling.

To enhance the rigor and reliability of the analysis, two independent researchers reviewed the codes and themes. Discrepancies were resolved through discussion and re-examination of the data. NVivo software was used to assist in organizing and managing the qualitative data during the analysis process.

## 6. Ethical Considerations

The study was conducted following ethical guidelines to ensure participant safety, privacy, and autonomy. Ethical approval was obtained from the ethics committee prior to the initiation of the study.

### Informed Consent:

All participants were provided with a detailed information sheet about the study's objectives, procedures, potential risks, and benefits. Informed consent was obtained from each participant before the interviews commenced.

### Confidentiality:

To maintain confidentiality, participants were assigned unique identifiers, and personal information was anonymized in all transcripts and reports. Audio recordings were stored securely on encrypted devices, and only the research team had access to the data.

### Emotional Support:

Given the sensitive nature of genetic disorders and decision-making, participants were informed that they could withdraw from the study at any time without consequence. Additionally, counseling services were offered to any participant who felt emotional distress as a result of discussing their genetic condition or decision-making experiences.

## 7. Trustworthiness and Rigor

Several strategies were employed to ensure the trustworthiness of the findings:

- **Credibility:** Prolonged engagement with participants during the interview process helped to build rapport and elicit deep, meaningful responses.
- **Triangulation:** Data from the interviews were compared with existing literature and hospital records (where appropriate) to ensure consistency and reliability.
- **Member Checking:** Participants were offered the opportunity to review and provide feedback on the transcribed interviews to ensure their responses were accurately captured.
- **Transferability:** Thick descriptions of the participants' experiences were provided to allow for potential transferability of findings to other contexts involving genetic counseling.
- **Dependability:** An audit trail documenting all decisions made during the research process was maintained, allowing future researchers to replicate or evaluate the study's methodology.

## Findings

From the data analysis, four main themes emerged that encapsulated the participants' experiences with genetic counseling: (1) Information as Empowerment, (2) Emotional and Psychological Support, (3) Decision-Making Confidence and Clarity, and (4) Uncertainty and Emotional Conflict. These themes, along with their respective sub-themes, are outlined below, accompanied by illustrative participant responses.

### Theme 1: Information as Empowerment

Participants consistently emphasized how the detailed information provided during genetic counseling helped them feel more in control of their health decisions. For many, the knowledge gained was transformative, enabling them to weigh the risks and benefits of their choices more effectively.

#### Sub-theme 1.1: Understanding Genetic Risk

Participants valued the ability of genetic counselors to break down complex genetic information in a way that was comprehensible and actionable. This empowered them to make informed decisions about their medical care and family planning.

- Participant 4 (Female, 35, hereditary cancer risk):

“Before counseling, I had no idea what BRCA1 even meant. But the counselor explained everything so clearly that I finally understood what my risk was, and that helped me decide on preventive surgery.”

#### Sub-theme 1.2: Personalized Guidance

Participants highlighted the importance of receiving personalized information relevant to their specific genetic condition. Rather than general information, they appreciated the individualized approach that considered their medical history and family background

- Participant 11 (Male, 42, muscular dystrophy):

“It wasn’t just generic advice. The counselor looked at my family’s history and really personalized the options for me and my kids. That made all the difference.”

### Theme 2: Emotional and Psychological Support

Emotional support was a recurring theme, with many participants describing the psychological relief they experienced during and after the counseling process. The ability of counselors to listen empathetically and provide emotional reassurance was seen as equally important as the medical information provided.

#### Sub-theme 2.1: Feeling Understood

Several participants expressed that the genetic counseling sessions made them feel understood and cared for, which was particularly meaningful as they dealt with the emotional burden of their diagnosis.

- Participant 7 (Female, 29, rare genetic disorder):

“I was so scared going into the session, but the counselor was so kind and patient. She made me feel like I wasn’t alone in this, and that really helped calm my anxiety.”

#### Sub-theme 2.2: Managing Anxiety and Fear

Participants described how counselors helped them manage feelings of fear and uncertainty, especially in relation to the potential outcomes of their genetic condition and the risk of passing it on to their children.

- Participant 14 (Female, 33, prenatal genetic risk):

“I was overwhelmed with the fear of having a child with the same condition, but the counselor walked me through all the options. It didn’t make the fear go away completely, but I felt better prepared.”

### Theme 3: Decision-Making Confidence and Clarity

Genetic counseling played a crucial role in helping participants feel more confident in their decision-making. By providing both emotional and informational support, counselors helped patients gain clarity regarding their next steps.

### Sub-theme 3.1: Clarity on Medical Decisions

Participants frequently mentioned that the counseling sessions provided them with the clarity they needed to make complex medical decisions, such as whether to pursue further testing, undergo preventive treatments, or consider family planning options.

- Participant 2 (Male, 39, hereditary heart condition):

“I was unsure whether to get the surgery or not, but after the counseling, it became clear that it was the best option for me. The counselor helped me see the bigger picture.”

### Sub-theme 3.2: Confidence in Family Planning Choices

For participants considering family planning, the genetic counseling process provided them with the knowledge and confidence to make decisions about having children, including the use of preimplantation genetic diagnosis (PGD) or other reproductive technologies.

- Participant 9 (Female, 37, cystic fibrosis carrier):

“The counseling gave us the confidence to go ahead with IVF and PGD. Without that guidance, we might have felt too scared to try.”

## Theme 4: Uncertainty and Emotional Conflict

While many participants felt empowered, some struggled with ongoing uncertainty and emotional conflict after receiving genetic information. These participants noted that, even with counseling, they felt burdened by the gravity of their decisions, especially in cases where the genetic risks were ambiguous or uncertain.

### Sub-theme 4.1: Difficulty Processing Information

Some participants felt that the complexity of the genetic information they received left them feeling overwhelmed, making it difficult to make clear decisions. This was particularly true for those who received results that were not definitive.

- Participant 12 (Male, 48, ambiguous genetic test results):

“The counselor explained everything, but it was so much information, and the results were still uncertain. I felt like I didn’t have a clear path forward.”

### Sub-theme 4.2: Emotional Weight of Decision-Making

Several participants expressed the emotional toll of having to make decisions that could impact their own health or their family’s future, even after genetic counseling. These participants often struggled with the weight of their decisions, particularly when they involved preventive surgeries or family planning.

- Participant 6 (Female, 31, hereditary cancer risk):

“Even though I knew what the right choice was for me medically, deciding to have preventive surgery was still emotionally difficult. The counseling helped, but it didn’t make the decision any less daunting.”

## Discussion

The findings from this study highlight the crucial role that genetic counseling plays in shaping the decision-making processes of patients with genetic disorders. The themes that emerged from patient experiences underscore the dual impact of genetic counseling: providing essential medical information and offering emotional and psychological support. While many participants found empowerment and clarity through counseling, others faced ongoing emotional conflict and uncertainty, suggesting that genetic counseling is a complex, multifaceted experience.



### 1. Information as Empowerment

One of the central findings of this study was the sense of empowerment patients gained from receiving clear, personalized information during genetic counseling. Consistent with previous research (Ramos, 2020), participants emphasized the importance of understanding their genetic risk and how that understanding informed their decisions about treatment, family planning, and lifestyle adjustments. By translating complex genetic information into a comprehensible format, counselors helped patients feel in control of their healthcare choices. This aligns with the work of Douma et al. (2010), who demonstrated that well-structured genetic counseling sessions improve patients' comprehension of genetic risks and options, ultimately leading to more informed decisions.

However, while most participants felt that the information provided was empowering, a minority still struggled with processing the complexity of genetic data. This reflects findings from Smerecnik et al. (2019), which suggest that patients with lower health literacy may find it difficult to grasp the full implications of genetic information, despite counseling. These results indicate a need for more tailored communication strategies to address the varying levels of health literacy among patients, ensuring that all individuals leave genetic counseling sessions with a clear understanding of their options.

### 2. Emotional and Psychological Support

Emotional and psychological support emerged as a key theme, with participants expressing gratitude for the empathy and care shown by genetic counselors. This finding is consistent with the literature, which highlights the dual role of genetic counselors as both medical and emotional support providers (MacLeod et al., 2021). Many participants noted that genetic counseling not only provided them with medical knowledge but also helped them manage feelings of fear, anxiety, and isolation. For example, patients facing hereditary cancer risks described how counselors alleviated their anxieties by helping them weigh the pros and cons of preventive surgeries or lifestyle changes, which is in line with research by Aspinwall et al. (2013) on the psychological impact of genetic counseling.

However, despite the emotional relief experienced by some, other participants expressed ongoing emotional conflict, particularly when the counseling resulted in uncertain or ambiguous genetic results. These findings align with research by Douma et al. (2010), which showed that patients often experience lingering uncertainty after genetic counseling, especially when genetic results do not provide definitive answers. This highlights a need for additional psychological support for patients who leave counseling sessions feeling uncertain or emotionally conflicted.

### 3. Decision-Making Confidence and Clarity

A significant number of participants reported that genetic counseling gave them confidence and clarity in making difficult health decisions. This reflects the findings of previous studies, such as those by Douma et al. (2010), which emphasize that the guidance provided in genetic counseling helps patients feel more secure in their choices, particularly regarding preventive measures and family planning. Participants in this study who were considering reproductive options, such as preimplantation genetic diagnosis (PGD), expressed how counseling provided them with the knowledge and confidence to proceed with these complex choices.

However, the emotional weight of these decisions was palpable for many participants, particularly those contemplating irreversible medical interventions, such as prophylactic surgeries. This emotional burden, despite the clarity gained from counseling, supports the findings of Aspinwall et al. (2013), who suggested that even well-informed patients may continue to experience psychological stress when faced with life-

altering decisions. These findings suggest that ongoing counseling or psychological follow-up may be necessary to support patients through the decision-making process, even after the initial counseling session.

#### 4. Uncertainty and Emotional Conflict

While many participants reported feeling empowered, others expressed ongoing uncertainty and emotional conflict, particularly when confronted with ambiguous or non-definitive genetic results. This finding is consistent with the work of Smerecnik et al.,(2019), which found that patients often leave genetic counseling with lingering uncertainties, especially when results are inconclusive. Some participants in this study felt overwhelmed by the responsibility of making complex decisions based on uncertain information, highlighting the need for genetic counselors to address both the informational and emotional needs of patients more thoroughly.

The emotional weight of decision-making, especially when considering preventive surgeries or family planning, also emerged as a challenge for participants. Even with clear information and support, some patients struggled with the gravity of the decisions they faced. This suggests that while genetic counseling provides crucial decision-making tools, it may not fully resolve the emotional complexities that accompany genetic risk management. Future interventions should focus on providing continuous emotional and psychological support, particularly for patients grappling with emotionally charged decisions.

#### 5. Implications for Practice

The findings from this study offer important implications for genetic counseling practices. First, there is a clear need for genetic counselors to adopt a more personalized approach to communication, tailoring their explanations to the patient's level of health literacy. This would ensure that all patients, regardless of their background, fully comprehend the genetic risks and options available to them. Additionally, the ongoing emotional and psychological support for patients dealing with uncertainty and emotionally charged decisions must be prioritized, potentially through follow-up counseling sessions or referral to mental health professionals when necessary.

Counselors should also consider extending their role beyond the initial counseling session to provide continued support as patients navigate the decision-making process. This could include offering patients additional resources, such as support groups or decision-making frameworks, to help them cope with the emotional burden of making life-altering choices based on genetic information.

#### 6. Limitations of the Study

This study was conducted at a single tertiary hospital, which may limit the generalizability of the findings to other healthcare settings. The sample size was relatively small, which is typical for qualitative research, but may not capture the full diversity of experiences among patients with genetic disorders. Additionally, while every effort was made to ensure the accuracy and depth of the interviews, participant recall bias may have influenced the responses, particularly regarding emotional and psychological experiences. Future studies could benefit from larger, more diverse samples and longitudinal designs to capture changes in decision-making and emotional responses over time.

#### 7. Future Research

Further research is needed to explore how genetic counseling influences long-term decision-making and emotional well-being. Longitudinal studies that follow patients over several years could provide insight into how decisions made during genetic counseling evolve over time and how patients continue to manage their

genetic risk. Additionally, research exploring the impact of cultural, social, and economic factors on the effectiveness of genetic counseling would provide valuable insights into how these variables influence patient outcomes, especially in diverse populations.

## Conclusion

In conclusion, this study underscores the importance of genetic counseling in empowering patients with genetic disorders to make informed, confident decisions while offering crucial emotional and psychological support. However, the emotional complexities and uncertainties surrounding these decisions require ongoing attention. By refining communication strategies and providing continuous emotional support, genetic counselors can better assist patients in navigating the often difficult decisions they face in managing their genetic risk.

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