

Effects of receiving genetic services on the practice of Genetic Counselors

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1. Introduction

We explored the experiences of genetic counselors that previously had genetic counseling/testing or were directly involved in the genetic care of a relative, to determine the impact of these experiences on their genetic counseling practice.

2. Methods

An anonymous survey was created with 17 multiple choice and 2 open-ended questions. The survey link was sent to a total of 262 genetic counselors employed at various centers nationwide. The inclusion criteria were genetic counselors who had genetic counseling/testing themselves, or who were involved directly in the genetic care of a close relative or friend.

3. Results

21 responses were collected from the survey. 52% of respondents received prenatal counseling, while the remaining 48% had either cancer, pediatric, or adult genetic care. The majority (67%) felt this experience benefitted their genetic counseling. 66% stated it increased their empathy towards patients, 33% incorporated lessons from their own journey into their practice, and 19% felt more comfortable with cases that emulated their own (Figure 1). Genetic counselors also noted that their genetic counselor status impacted the care that they received. Many (43%), reported providers skipping wanted details due to an assumption of knowledge. Some (19%) felt they received higher quality care because the provider knew they were a genetic counselor. One participant said “I felt it would have been fine if it was just me, but my partner was on the call and the genetic counselor barely explained anything.” Most (90%) respondents were satisfied with their care.

4. Discussion

One notable impact of the personal experience as a patient was that it increased the genetic counselors’ empathy toward their patients (Figure 2): “I have a better understanding of what it feels like to wait for results— it can be unbearable! I now have more empathy and understanding for patients who call over and over for results.” Another impact was that many genetic counselors (57%) use disclosure of their personal experience to build rapport. (Figure 2) “I had prenatal genetic counseling because I am a carrier of an AR condition and chose to have a CVS. I will sometimes explain to patients who are concerned over having discovered that they are a carrier of a condition that I myself am also a carrier of a condition (as are most people) and I find that helps put them at ease.” Finally, some genetic counselors found they avoided things that negatively impacted their own patient experience (19%), while others added skills to their practice that they appreciated during their own time as patient (33%). Of note, one genetic counselor mentioned a negative consequence their personal patient experience had on their practice noting, “I have had a handful of patients with very similar stories to mine and experienced counter-transference and another GC in the practice had to take over the case.”

5. Conclusions

Overall, genetic counselors found being a patient a mostly positive experience. Participants found that these experiences led to increased empathy and rapport building with their own patients. However, disadvantages of being a genetic counselor while receiving genetic services included receiving less information from providers.

Tables + Figures

Figure 1. Impact of personal genetics experience on GC practice

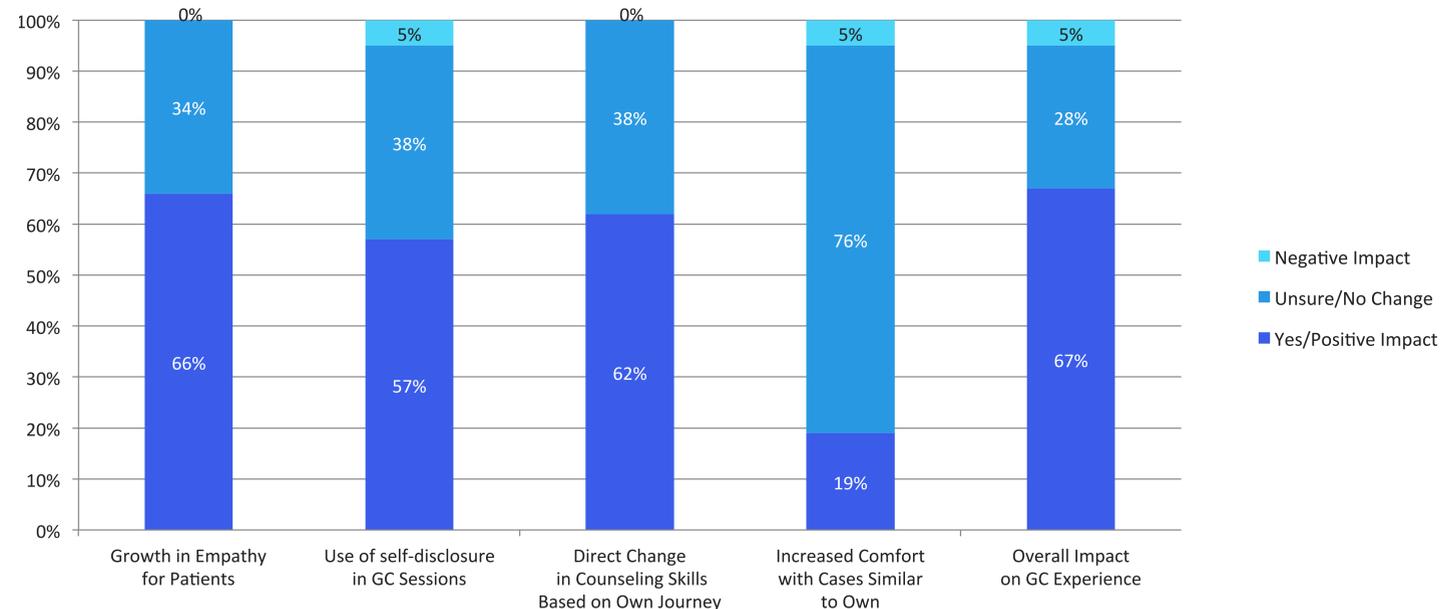


Figure 2. Using personal experience to further GC skills

Empathy

- “I have a strong appreciation for the patient experience with regard to navigating a complex healthcare infrastructure. I can empathize with the anxiety of waiting for the next scan, waiting for the difficult news but feeling relieved when it doesn’t come, etc.”

Disclosure

- “Since my sibling was found to have a very rare condition, when I meet families whose children have the same thing I hope that it makes it seem less rare and less daunting that their GC is related to someone with the same condition (CHARGE syndrome)”

Rapport

- “I don’t know that it impacted their clinical care, but it increased their trust in me”
- “I think patients feel more comfortable with me when I disclose my family history of genetic testing. Most visibly become more relaxed since I have “been in their shoes” so to say”