

Patient satisfaction with Genetic Results Counseling services

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I. Introduction

Genetic Results Counseling (GRC) services were developed by our group to increase patient access to genetic counseling expertise. The service is available for patients with abnormal carrier screening or non-invasive prenatal test results. GRC is limited to a discussion of the abnormal results, an overview of the disorder for which the patient is at increased risk, and a discussion about follow up testing options. Depending on the preference of the ordering provider, the patient may either be initially informed about their results by the genetic counselor (GC) or by the patient's ordering health care provider. In our current study, 2/3 of the patients were informed of their result by the GC at the beginning of the session and 1/3 of the patients were informed by their healthcare provider and subsequently referred for GRC. The purpose of this study was to evaluate patient satisfaction with the GRC service.

II. Methods

Patients seen for GRC during a 4-month period were provided a survey regarding their experience. The survey contained seven statements (Table 1) to assess patient satisfaction; six validated for the clinical genetics setting, and one about the service. A Likert scale of 1 (strongly disagree) to 5 (strongly agree) was utilized for the statements, with averages calculated for each item. Finally, patients were queried about their preference regarding who informs them of their test results, with multiple choice answers. Patients chose whether they preferred to have their healthcare provider or a genetic counselor inform them of their test results or if they had no preference.

Table 1: Survey statements evaluated by Likert scale

Survey Statements
My genetic counselor listened carefully to what I said.
My genetic counselor explained things in a way that was easy to understand.
I received the information I needed from my genetic counselor.
My genetic counselor helped me feel like a partner in care.
My genetic counselor spent enough time with me.
My genetic counselor answered all my questions.
I would recommend this genetic counseling service to a friend or colleague.

III. Results

Overall, we found that patients were highly satisfied with GRC. Based on the average of responses (Figure 1), they felt the GC listened (4.77), explained the information (4.79), answered all their questions (4.82), and they received the information they needed (4.76). In addition, they were very satisfied with the length of the session (4.71), felt like a partner in care (4.59), and would recommend the service to a friend (4.61).

Patients were asked about whether they would have preferred to have their health care provider or the GC initially inform them of their abnormal results. Although 47% of patients had no preference, when they did have a preference, they were two times more likely to select the GC (35%) over their health care provider (HCP) (17%). Patients who were informed by their health care provider experienced speaking to both their provider and a genetic counselor about their results, and may be better able to indicate a preference. When evaluating the responses from patients who were informed by their HCP (Figure 2), 46% of patients indicated that they prefer to be informed about their results by a genetic counselor and only 16% preferred to be informed by their provider. The remaining 38% had no preference.

Figure 1. Average response to each statement

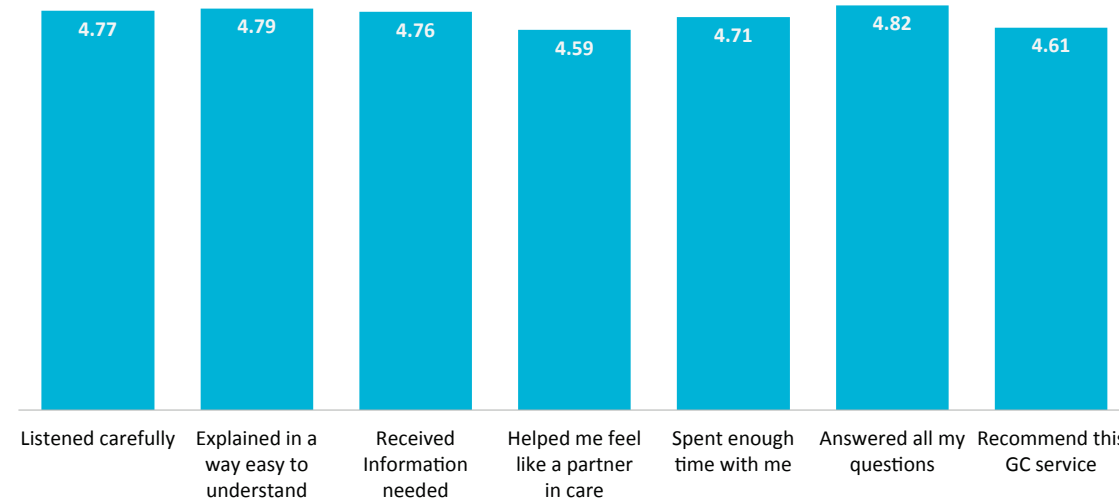
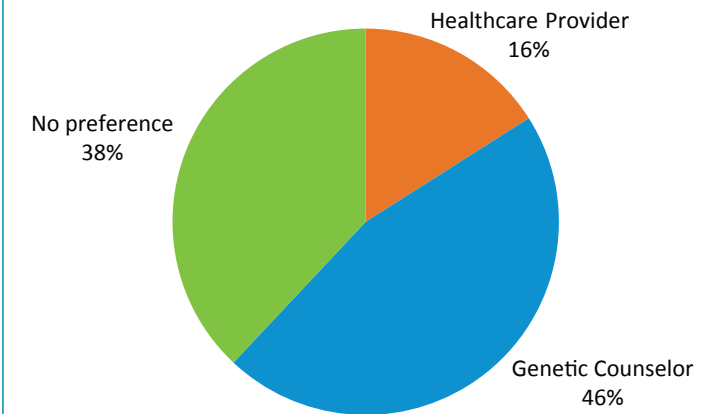


Figure 2. Patients informed by Healthcare Provider before Genetic Counselor



IV. Conclusions

Genetic Results Counseling was shown to be a highly effective approach to providing patients with information about abnormal carrier screening or NIPT results. Patients showed a preference towards initially receiving their results from a GC, giving the patient immediate access to the health care provider most suited to answering their questions. Our study demonstrated that genetic results counseling is an effective option to increase patient access to GC expertise.