



# Proxy Patients' Perceptions of Genetic Counselor Empathy Responses



Jennine Deckert, MS, CGC, Pat McCarthy Veach, PhD<sup>1</sup>, Ian M. MacFarlane, PhD<sup>1</sup>, Janice Baker, MS, LGC<sup>2</sup> and Krista Redlinger-Grosse, PhD, LP, ScM, LGC<sup>1</sup>

<sup>1</sup>Department of Genetics, Cell Biology, and Development, University of Minnesota, Minneapolis, MN, USA; <sup>2</sup>Children's Minnesota, Minneapolis, MN, USA

## Background & Purpose

**Background:** Empathy is the ability to understand another person's experience and to communicate that understanding. Studies suggest counselor empathy can positively affect genetic counseling processes and outcomes.<sup>1,2,3,4,5</sup> Yet no studies have investigated patients' perceptions of genetic counselor responses intended to convey empathy.

**Purpose of the Study:** This study investigated the types of genetic counselor responses proxy patients perceive as most empathic and why.

### Research Questions:

- 1) What types of genetic counselor-defined empathy responses do proxy patients perceive as most empathic?
- 2) What are proxy patients' rationales for their choice of responses they perceive as most empathic?
- 3) Do rationales differ based on proxy patient demographics?

## Methods

Female proxy patients (n=198) recruited through Amazon MTurk completed a survey containing demographic items, definition of empathy, and two hypothetical genetic counseling scenarios (Fabry disease and a postnatal diagnosis of cleft lip and palate). Each scenario described the condition and ended with a patient statement followed by five different genetic counselor empathy responses from a prior study of expressed empathy.<sup>5</sup> For each scenario, participants identified the response that best conveyed empathy and their rationale for choosing that response. Thematic analysis yielded common themes in rationales. Logistic regression analyses determined predictors of each rationale provided.<sup>7</sup>

## Scenarios

### Fabry Disease

#### Patient Statement

*"The episode of pain in my hands and feet are impossible to describe because the pain is so personal and out of control when it comes... The severe abdominal cramping is a sudden onset pain that is scary, and something you're not sure you can survive. It actually feels like it might kill you. Many times I have passed out – I just hope and pray if I pass out the pain will be over when I come back... if I come back."*

#### Genetic Counselor Responses

- 1) It sounds like the pain associated with this condition has had a severe impact on your life and it is something that you think about very often....
- 2) It sounds like your pain makes you feel out of control and helpless.
- 3) That type of pain must be very difficult to live with and to never know when it may come, that must be very unsettling. Are there times you just wish you'd pass out?
- 4) Pain management can be quite difficult, especially when you don't know when the pain will start, or where it will be. It must make your life very difficult and unpredictable.
- 5) I'm very sorry to hear that you are in such pain. It's hard for me to imagine these episodes that you describe. I would like to try to help you find a physician/pain management group to help you.

### Cleft Lip and Palate

#### Patient Statement

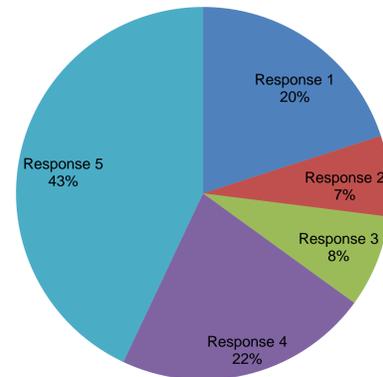
*"The first words I heard from the doctor were, 'Oh, my'... They said it was something that was fixable and not something to be majorly worried about. I didn't quite like it at all. I heard the 'Oh, my,' my husband fainted, and I thought something was majorly wrong. I actually thought maybe the baby was dead or something."*

#### Genetic Counselor Responses

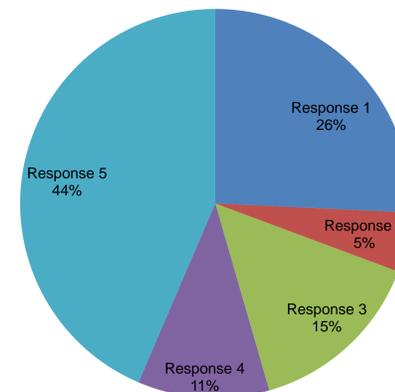
- 1) When you heard that initial reaction from the doctor, it made you feel something was very wrong. Hearing the news that way was upsetting.
- 2) You were really scared to find out what the doctor was talking about.
- 3) That must have been difficult, tell me what happened next.
- 4) Sometimes doctors and those present in the room react to what they are seeing without thinking about how their reactions will affect you.
- 5) I'm so sorry that you had that experience with the birth of your child. Hearing those words from the mouth of the doctor must have been awful.

## Frequency of Genetic Counselor Response Selection

Fabry Disease Scenario



Cleft Lip and Palate Scenario



Responses containing "I'm sorry" were most selected in both the Fabry and Cleft Lip and Palate scenarios

## Conclusion and Discussion

- Proxy patients differed in their preferences for empathy responses, as each genetic counselor-defined empathy response was selected at least once in both scenarios.
- Patients want from an empathy response differs depending on their genetic situation
- While "I'm sorry" was a component of a preferred response, relatively few participant rationales were in the Sympathizing category.
- There was little consistency across response rationales and several responses predicted multiple rationales
- Predicting the type of response patients may find as most empathic using demographic variables is not a recommended strategy based on our data.
- Empathy is an ongoing process and the understanding of the patient's experience will increase over time.
- Ongoing assessment of patients' feelings and needs (empathic resonance) will allow genetic counselors to tailor their empathy communication accordingly.

## Respondents' Rationales for Their Preferred Responses

Thematic analysis yielded five rationale themes

**Understanding** - participant statements that the genetic counselor conveyed a recognition of the patient's experience and/or feelings.

- Sample Response: *"Makes it sound like counselor understands both the level of pain and the impact on the life situation."*

**Problem Solving** - statements that the counselor conveys a willingness to help, fix or find a solution for the patient.

- Sample Response: *"Because the counselor cannot relate to the pain herself, explains this, and offers Sarah assistance in finding someone who might be able to help her manage that pain during episodes."*

**Sympathizing** - statements that the counselor expressed compassion for what the patient had experienced.

- Sample Response: *"It's very apologetic and the most sympathetic response towards the bad experience the couple had with the doctor."*

**Focusing on Patient** - statements that the genetic counselor directed attention in the conversation to the patient.

- Sample Response: *"This invites the patient to talk more about their pain."*

**Validating** - statements that the counselor provided support for the patient's feelings.

- Sample Response: *"Validation without trivializing her experience or justifying the other doctor's response"*

## Prediction of Response Rationale Fabry Disease

Regression analyses showed significant predictors varied across scenarios and between rationales, though few demographic predictors were significant.

### Understanding

- Choosing response 4 increased likelihood of using this rationale
- Being single increased likelihood of using this rationale

### Problem Solving

- Choosing responses 1, 2 or 3 decreased likelihood of using this rationale

### Focusing of Patient

- Choosing response 1 or 3 increased likelihood of using this rationale
- Having children decreased likelihood of using this rationale

### Validating

- Having children increased likelihood of using this rationale

## Prediction of Response Rationale Cleft Lip and Palate

Regression analyses showed significant predictors varied across scenarios and between rationales, though few demographic predictors were significant.

### Understanding

- White participants and those with income between \$50-100K per year were more likely to provide this rationale
- Selection of responses 2, 3 or 4 decreased the likelihood of using this rationale

### Sympathizing

- White participants were more likely to use this rationale
- Selection of response 1 decreased likelihood of using this rationale

### Focusing of Patient

- Choosing response 3 decreased likelihood of using this rationale

### Validating

- Participants with income greater than \$100 and those who had previously heard of genetic counseling were more likely to use this rationale
- White participants and those with a Bachelor's or Graduate degree had a decreased likelihood of using this rationale

## Study Limitations and Research Recommendations

- Use of hypothetical genetic counseling scenarios and proxy patients
- Use of written genetic counselor responses as opposed to in person responses means responses lacked verbal (e.g., tone) and non-verbal (e.g., body language) cues.
- Empathy responses used in this study derived from Kao (2010) were exemplars of specific categories from Kao (2010), and some were more complex than others
- Further studies could more accurately simulate real sessions such as video recorded sessions or hypothetical in-person sessions
- Future studies may also involve other hypothetical genetic counseling scenarios and additional genetic counselor empathy responses

## Practice Implications

- There is not a single preferred empathy response for all patients
- Ongoing assessment of the patient's feelings and needs facilitates an effective empathic response
- Counselors must recognize individual patient needs and tailor their empathy responses for each patient and not base their assessment on demographic variables

## References

- [1] Ellington, L., Kelly, K., Reblin, M., Latimer, S., & Roter, D. (2011). Communication in Genetic Counseling: Cognitive and Emotional Processing. *Health Communication*, 26(7), 667-675.
- [2] Bachelor, A., & Freedheim, Donald K. (1988). How Clients Perceive Therapist Empathy: A Content Analysis of "Received" Empathy. *Psychotherapy: Theory, Research, Practice, Training*, 25(2), 227-240.
- [3] Kunyik, D., & Olson, J. (2001). Clarification of conceptualizations of empathy. *Journal of Advanced Nursing*, 35(3), 317-325.
- [4] Duric, V., Butow, P., Sharpe, L., Lobb, E., Meiser, B., Barratt, A., & Tucker, K. (2003). Reducing psychological distress in a genetic counseling consultation for breast cancer. *Journal of Genetic Counseling*, 12, 243-264.
- [5] Kao, Juihsien H.. (2010). Walking in your patient's shoes: an investigation of genetic counselor empathy in clinical practice.. Retrieved from the University of Minnesota Digital Conservancy.