

Skillfulness is in the Eye of the Beholder: Genetic Counselors' and Proxy Patients' Perceptions of Genetic Counselor Responses to Self-Disclosure Requests



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Introduction

Research suggests patients' motivations for requesting self-disclosure from genetic counselors include seeking guidance, looking for validation, respecting the genetic counselor's opinion, and building the counselor-patient relationship (Thomas et al., 2006). Balcom et al. (2013) found the most frequently requested type of self-disclosure by prenatal patients was, "What would you do in my situation?". The researchers identified four types of genetic counselor responses to a patient request for self-disclosure: Personal disclosure, professional disclosure, redirection, and decline to disclose. Redlinger-Grosse et al. (2013) found genetic counselors responses to a hypothetical prenatal patient yielded a range of disclosures and non-disclosures, suggesting skillfulness matters more than response type.

Purpose

- (1) Assess which types of responses to a prenatal patient request for self-disclosure genetic counselors (GCs) and proxy patients (Pxy PTs) perceive as most skillful;
- (2) Determine if GCs differ from Pxy PTs in ratings of response skillfulness;
- (3) Look for differences in participants' perceptions as a function of demographics.

Methods

Sample and Procedures

- Participant sample: 1) Genetic counselors (GC): recruited from NSGC listserv. Inclusion criteria: current practice in a clinical or non-clinical setting in North America, and ABGC certified or board eligible. 2) Proxy patients (Pxy Pt): recruited through Amazon's Mechanical Turk marketplace. Inclusion criteria were: female, over the age of 18, and residing in the U.S.
- Participants completed a survey involving a hypothetical prenatal scenario where the patient asks the GC, "What would you do?" and several possible GC responses (Table 1).
- GC responses were constructed from the most frequent hypothetical responses in Redlinger-Grosse et al. (2013) and included: non-disclosures (NSD) (redirection or decline to disclose) and self-disclosures (SD) (personal or professional).
- For each of the four SD and NSD types there was an interpretive, reassuring, corrective, guiding, and literal response.
- Participants were randomized into either a survey with SD or NSD responses and asked to rate response skillfulness (Scale: 1=unskillful to 6=skillful).
- Next, they chose the response they perceived as most skillful and explained their selection.

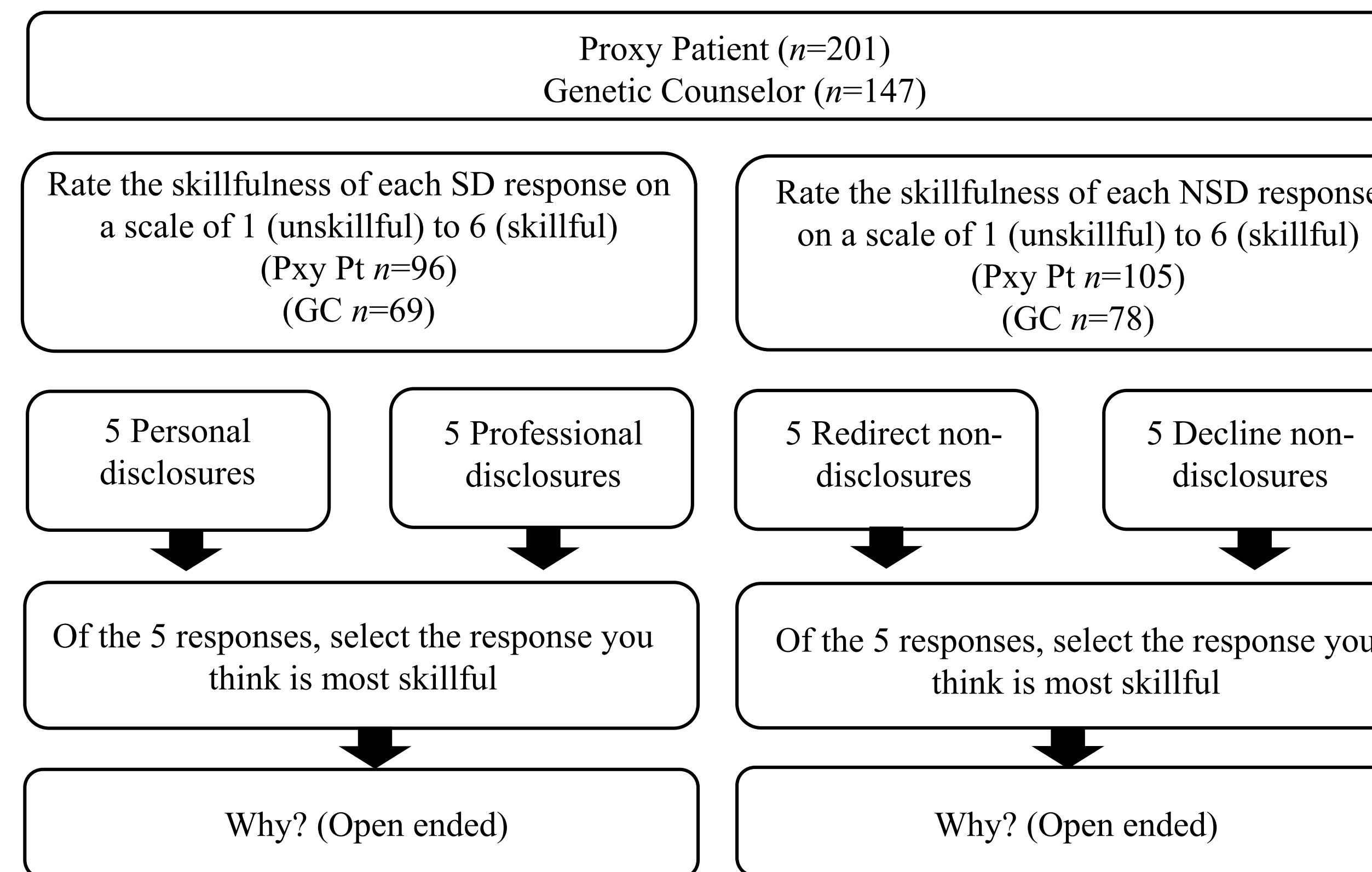
Analysis

- This study was a 2x2x2 mixed, nested design.
- A multivariate analysis of variance (MANOVA) assessed main and interaction effects of participant group, self-disclosure condition, and specific response type on skillfulness ratings of counselor responses.
- Participant explanations of the response they chose as most skillful were categorized using a *priori* framework of GC intentions from Redlinger-Grosse et al. (2013).

Table 1. Genetic Counselor Responses to Patient Question "What Would You Do?"

	Interpretive	Reassuring	Corrective	Guiding	Literal
Professional SD	"In my experience, some women are concerned about the risk of an amniocentesis and what an abnormal result means to them. Is this something you're concerned about?"	"I get asked this a lot by patients. Many of my patients are uncertain of what they want to do. I don't think there's a wrong choice, but there is a best choice for you."	"A lot of people have asked me that, but what I would do doesn't matter. I see women in your position every day, and they all make their decision for different reasons."	"Other patients I've seen in this situation often think about their families, their values, and what they would do with the results from the amniocentesis."	"Other patients that I have seen in this situation have chosen to proceed with the amniocentesis, too."
Personal SD	"I don't know what I would do. It is a lot to think about. But, you said that you came here with good reasons for having the amniocentesis. Has that changed?"	"I would do exactly what you're doing and think about all the reasons to have an amniocentesis, and all the reasons to not have an amniocentesis. It's very normal to have these conflicting thoughts."	"In all honesty Katie, I'm not sure what I would do. I'm not you and I can't truly know what you are feeling right now."	"I'm not trying to avoid your question, but many factors go into this decision. If I were you, I'd consider how much I wanted to know if there's a chromosome problem versus the risks of the procedure. Then I'd decide what would make me the most comfortable during the pregnancy."	"I'm not sure. However, based on everything you have told me today, if I were you, I would move forward with the amniocentesis."
Redirecting NSD	"Perhaps you're asking what I would do because you're feeling unsure about wanting an amniocentesis?"	"This is a tough decision. Let's talk about the issues you're thinking about, so you can make the choice that is best for you and your family."	"That answer depends on many things. It's really a personal decision. Let's focus on what's most important to you."	"Well, there are a number of factors that go into a decision like this. Why don't we re-visit your options now and talk through what each scenario may bring."	"Well, let's go over some of the options again."
Decline to disclose NSD	"It's a very personal decision, and I can't say what I would do. Perhaps the information we discussed has you questioning your original plan?"	"I really cannot answer that. But we can talk through the different options so you can reach a decision that's best for you."	"I'm not you and this is a very personal decision. Only you can answer that question. What I would do might not necessarily be what is best for you."	"I really can't answer that. I want to help you weigh your priorities and concerns and find the right decision for you. Let's think about what's important to you."	"This is a difficult question. I can't say what I would do."

Results



- Pxy PTs were on average 36.9 years old (Range 19-71), Caucasian (72.8%), and had an Associate's or Bachelor's degree (50.5%).
- Pxy PTs had little/no familiarity (32.3%) to some familiarity (39.3%) with genetic counseling.
- GCs were on average 32.6 years old (Range 24-67), Caucasian (95.2%), and had 6.5 years of experience (Range 1-35 yrs).
- GCs reported they were unlikely to disclose personal experiences (60.5%) but likely to disclose professional experiences (66%).

Likert Ratings of Response Skillfulness

Table 3. Estimated Marginal Means and Standard Error for Proxy Patient and Genetic Counselor Ratings

	Interpretive	Literal	Corrective	Guiding	Reassuring
	Marginal Means (SE)	Marginal Means (SE)	Marginal Means (SE)	Marginal Means (SE)	Marginal Means (SE)
Professional SD					
Pxy Pt (n=96)	4.52 (.13)	2.85 (.12)	3.37 (.15)	3.76 (.14)	4.33 (.13)
GC (n=69)	3.84 (.17)	1.42 (.15)	2.67 (.17)	4.25 (.17)	4.07 (.16)
Personal SD					
Pxy Pt (n=96)	3.93 (.15)	3.40 (.12)	2.87 (.14)	4.67 (.13)	4.68 (.12)
GC (n=69)	4.22 (.17)	1.59 (.15)	2.30 (.17)	4.59 (.15)	4.45 (.14)
Decline NSD					
Pxy Pt (n=105)	3.35 (.12)	2.10 (.12)	3.08 (.14)	4.22 (.14)	4.15 (.13)
GC (n=78)	4.00 (.15)	1.79 (.14)	3.31 (.16)	3.96 (.16)	3.07 (.15)
Redirect NSD					
Pxy Pt (n=105)	3.20 (.14)	4.03 (.12)	4.51 (.14)	4.96 (.12)	4.98 (.11)
GC (n=78)	4.00 (.16)	1.84 (.14)	4.64 (.16)	4.39 (.14)	4.99 (.13)

Note. Ratings are based on a six-point scale where 1=unskillful and 6=skillful. The number of participants in each condition varies due to randomization. Marginal means address unequal sample sizes

- Lowest skill rating for **Pxy PTs**: Literal decline NSD (2.10)
-This is a difficult question. I can't say what I would do.
- Lowest skill rating for **GCs**: Literal professional SD (1.42)
-Other patients that I have seen in this situation have chosen to proceed with amniocentesis too.
- Highest rating for **both groups**: Reassuring redirect NSD (Pxy Pt 4.98 & GC 4.99)
-This is a tough decision. Let's talk about the issues you're thinking about, so you can make the choice that is best for you and your family.

Most-Skillful Response Selection

Table 4. Frequencies of Responses Selected by Proxy Patients and Genetic Counselors as the Most Skillful

	Interpretive n (%)	Literal n (%)	Corrective n (%)	Guiding n (%)	Reassuring n (%)
Personal SD^a					
Pxy Pt (n=96)	8 (8.3)	5 (5.2)	6 (6.3)	41 (42.7)	36 (37.5)
GC (n=69)	19 (27.5)	0(0.0)	0 (0.0)	31 (44.9)	19 (27.5)
Professional SD^a					
Pxy Pt (n=96)	31 (32.3)	10(10.4)	9 (9.4)	15 (15.6)	31 (32.3)
GC (n=69)	15 (21.7)	0 (0.0)	2 (2.9)	26 (37.7)	26 (37.7)
Decline NSD^a					
Pxy Pt (n=105)	11 (10.5)	5 (4.8)	11 (10.5)	50 (47.6)	28 (26.7)
GC (n=78)	25 (32.1)	0 (0.0)	15 (19.2)	33 (42.3)	4 (5.1)
Redirect NSD^a					
Pxy Pt (n=105)	2 (1.9)	6 (5.7)	20 (19.0)	43 (41.0)	34 (32.4)
GC (n=78)	14 (17.9)	0 (0.0)	16 (20.5)	13 (16.7)	34 (43.6)

Note. Each participant selected two responses; ^aFisher's exact test overall row differences significant at p<.001; SD=Self-disclosure; NSD=non-disclosure.

- None of the GCs selected a literal response that answers the question at face value as the most skillful.
- None of the GCs selected corrective personal self-disclosure as the most skillful
-In all honesty Katie, I'm not sure what I would do. I'm not you and I can't truly know what you are feeling right now.
- Literal and corrective responses were selected as most skillful by low percentages of both participant groups.
- No response was selected as most skillful by half or more participants in either group.

Results

Explanations of Choice of Most Skillful Response

Table 6. Qualitative Categories of Pxy Pt and GC Perceptions of the Most Skillful Response

Category	Pxy Pt Quote	GC Quote
Corrective: remind pt. her situation differs from the GC	"...it's a personal choice, and that what the counselor would do might not be the best choice for Katie." (Decline to Disclose NSD)	"It reminds the patient that the decision is personal and unique to her own circumstances." (Decline to Disclose NSD)
Focus on Patient: maintain focus of conversation on the pt	"This response makes it all about the patient, not about the counselor." (Professional SD)	"Focusing back to the needs of the patient." (Redirect NSD)
Guiding: attempt to facilitate decision-making	"Gets her to clarify her concerns to move forward in decision making." (Professional SD)	"Facilitates decision making by weighing the patient's top priorities." (Decline to Disclose NSD)
Interpretive: offer GC insight into pt. reasons for the question	"The counselor was trying to get to the root of what is causing Katie's hesitancy." (Professional SD)	"Creating and expressing a 'hunch' about the situation/patient response." (Decline to Disclose NSD)
Literal: take the question at "face value"	"It provides the patient with the most information." (Redirect NSD)	"...outlines specifically what reasons to consider." (Personal SD)
Promotes Autonomy: promote pt. decision independent from GC opinion	"Offers help without giving a biased opinion." (Decline to Disclose NSD)	"Makes patient consider that her decision should not be influenced by others." (Professional SD)
Reassuring: support or validate pt.	"It alleviates her fear that she will make the wrong choice by assuring her there is no such thing." (Professional SD)	"It normalizes her feelings and affirms that there is no wrong choice." (Professional SD)

- Focus on patient category was more prevalent in Pxy PT's explanations
- Promotes autonomy was more prevalent in GC's explanations

Discussion

Demographic Differences

- There were no significant differences in perceptions of skillfulness due to GC years of experience, Pxy Pt age, or Pxy Pt parental status.

Genetic Counselor & Proxy Patient Similarities and Differences

Similarities:

- Across the SD and NSD response types, guiding responses, followed by reassuring responses were rated highly by both groups. These response types, respectively, reflect the Reciprocal Engagement Model (REM) (McCarthy Veach et al., 2007) goal of facilitating collaborative decisions, and facilitating patient's feelings of empowerment and the REM tenet that patient feelings matter.
- Corrective responses received low Likert ratings by both groups and were selected less often as the most skillful response.
- Both groups viewed responses as skillful when they acknowledged/addressed the patient's hypothetical question, returned focus to the patient, provided reassurance/support, and provided guidance.

Differences

- GCs choose interpretive responses more frequently as the most skillful response. These responses relate to the REM goal of recognizing patient concerns and helping patients gain new perspectives. Pxy PTs may be unaccustomed to these responses, however, if they expect to receive paternalistic healthcare or feel threatened by this type of response.
- Pxy PTs rated literal responses higher than genetic counselors and selected literal responses more frequently as the most skillful. This may be due to a preference or expectation that patients play a passive role in decision making.

Practice Implications

- Skillful responses to patient requests for self-disclosure convey guidance and reassurance.
- No single response is universally perceived as most skillful.
- Individual patients will interpret genetic counselor responses uniquely and differ in their perceptions of skillfulness.

Study Limitations

- Written scenario could not assess response GC tone and nuance.
- Participant samples were non-random.
- GC responses selected from Redlinger-Grosse et al. (2013) may not reflect all possible responses.

Research Recommendations

- Research designs that can assess tone of voice and timing of SD or NSD.
- Studies using other genetic counseling specialties and other self-disclosure requests.
- Research involving actual genetic counseling patients.

Selected References

- Balcom, J. R., Veach, P. M., Bemmels, H., Redlinger-Grosse, K., & Leroy, B. S. (2013). When the topic is you: Genetic counselor responses to prenatal patients' requests for self-disclosure. *Journal of Genetic Counseling*, 22(3), 358-373.
- McCarthy Veach, P., Bartels, D.M., & LeRoy, B.S. (2007). Coming full circle: A Reciprocal-Engagement Model of genetic counseling practice. *Journal of Genetic Counseling*, 16, 713-728.
- McCarthy Veach, P. (2011). Reflections on the meaning of clinician self-reference: Are we speaking the same language? *Psychotherapy*, 48(4), 349-358.
- Redlinger-Grosse, K., Veach, P. M., & MacFarlane, I. M. (2013). What would you say? Genetic counseling graduate students' and counselors' hypothetical responses to patient requested self-disclosure. *Journal of Genetic Counseling*, 22(4), 455-468. <https://doi.org/10.1007/s10897-012-9568-9>
- Thomas, B. C., Veach, P. M., & LeRoy, B. S. (2006). Is self-disclosure part of the genetic counselor's clinical role? *Journal of Genetic Counseling*, 15(3), 163-177.