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## The Development and Testing of the Genetic Counseling Communication Checklist (GCC): A Novel Process Measure

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The Development and Testing of the Genetic Counseling Communication Checklist (GCC):

A Novel Process Measure

by

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A thesis submitted in partial fulfillment  
of the requirements for the degree of  
Master of Science  
with a concentration in Genetic Counseling  
Department of Global Health  
College of Public Health  
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## ABSTRACT

Given that genetic counseling (GC) is a discipline that relies on communication to help people understand and adapt to the genetic contribution of disease, a practical method of comprehensively documenting GC communication strategies is needed to better understand the communication strategies utilized by genetic counselors and the variability that exists within the process. To this end, we created a novel process measure called the Genetic Counseling Communication Checklist (GCC), utilizing previously validated measures, communication/counseling theories, and research findings. Two researchers independently coded six video-taped mock GC sessions using the GCC. Following each session, the GCC was further modified to improve clarity, content validity, and reliability. Reviewers agreed on category ratings for four of the eight categories during the initial rounds of review (i.e. 50% agreement between raters) . By the last two cases there were no disagreements in category ratings (though variation continued in whether a few items were checked). The final GCC contains 4 to 8 items within each category and successfully captures all major communication strategies implemented by counselors in the video sessions. The next step will be to pilot the GCC in real-world GC sessions.

*Keywords:* genetic counseling, process measures, communication, skills, strategies.

## INTRODUCTION

Genetic counseling (GC) is a discipline that relies on the communication between counselors and their patients to provide understanding of genetic contribution of disease and help patients make decisions about their genetic health. How well counselors communicate with their patients is expected to dictate success in achieving both provider and patient goals. It is therefore of the utmost importance to better understand the communication strategies and skills utilized by genetic counselors. A growing amount of research is being conducted on specific GC outcomes, such as patient understanding and empowerment (see for example McCallister et al., 2012); however, limited research has been conducted on the communication strategies employed by genetic counselors to achieve these outcomes (Berkenstadt, M., Shiloh, S., Barkai, G., Katznelson, M. B., & Goldman, B.; 1999 .; Borle et al., 2018; Slomp et al., 2018; Lobb et al., 2004). Before researchers successfully link communication strategies with patient outcomes, we must improve our understanding of which strategies are implemented in real world practice (Cragun & Zierhut, 2018; Street et al., 2008). A key first step is developing a pragmatic method for capturing and distinguishing between communication strategies used within a GC session.

Genetic counselors can make use of many different communication strategies and each counselor may have their own unique communication style. For example, one counselor may conduct their session in a question and answer format, where the patient is listening while the genetic counselor is providing information; another counselor may use a more “client-focused” approach where both the patient and counselor are involved in exchanging information in



relatively equal proportion (Ellington, 2006). Researchers have previously described differences between the educational model of GC and the counseling model (Kessler, 1997). Researchers have successfully broken these two models down further into subcategories using the Roter Interaction Analysis System (RIAS) to code transcripts of GC sessions with simulated patients (Ellington et al., 2006 & Roter et al., 2006). Yet, one limitation in using RIAS is that it does not distinguish between different strategies that may be employed to achieve specific GC goals. For example, RIAS is not designed to capture whether a mutual agenda is agreed upon during a session or whether the “teach-back” strategy is employed to check for patient understanding. Furthermore, the RIAS coding system requires coding of each statement within a clinical encounter, thereby making it impossible to code in real time.

The need for a practical process measure that can distinguish between communication skills in healthcare has previously been identified. Two measures have been created to evaluate communication skills during doctor-patient consultations (Burt et al., 2014; Novack et al., 1992). The Global Consultation Rating Scale (GCRS) rates communication interactions on a 3-point scale of “2. Good”, “1. Adequate”, to “0. Not Done/Poor”. Each rating correlates to a specific point value, which can then be summed to give an overall score. The measure was found to be useful in linking identified potential training needs to an established approach of teaching communication skills. The Brown Interview Checklist (BIC) predominately uses a “yes/no” format to indicate whether specific skills are completed (Novack et al., 1992). A checklist has also been designed to provide a reliable means of assessing risk communication skills used by genetic counselors during their sessions (Fransen, Meertens, & Schrandt-Stumpel, 2006). However, none of these checklists or scales were designed to cover a broad range of genetic counseling skills or communication strategies.

Therefore, our research focused on creating a new process measure, the Genetic Counseling Communication Checklist (GCC) that was designed to capture specific communication strategies commonly used by genetic counselors in patient sessions. We evaluated the practicality, inter-rater reliability, and content validity of the GCC and further revised to improve these aspects.

## METHODS

### Development of the GCC

The GCC began as a modified version of the Global Consultation Rating Scale with additional items added from Brown Interview Checklist, and a previous genetic counseling checklist that focused solely on risk communication (Burt et al., 2014; Novack et al., 1992; Fransen, Meertens, & Schrandner-Stumpel, 2006). Revisions were made by KH and DC through an iterative process involving review of the literature and multiple discussions. This process will be explained further within the results section. Additional content of our checklist was created using elements of the Reciprocal Engagement Model (REM) of genetic counseling and the Framework for Outcomes in Clinical Communication Services (FOCUS) (Cragun & Zierhut, 2018; Veach et al., 2007). These models provided us with the goals and tenets of an ideal genetic counseling session as well as some of the behaviors and skills categories.

A targeted literature review was conducted to ensure the inclusion of skills that are proven effective or are commonly cited as being useful in patient-provider communication. This review consisted of searching scholarly sources for research on each of the skill categories, specifically focusing on findings that were found to improve communication within each domain. Through this process, a total of eight skills categories were ultimately decided upon that align with categories of the Communication Skills Domain of the Framework for Outcomes in Clinical Communication Services (FOCUS).

## Evaluation of the GCC

This study was determined by the University of South Florida's Institutional Review Board to be an evaluation study of the GCC and did not fall under the purview of human subject's research. To test and improve inter-rater reliability of the GCC, the first author (KH), who is a genetic counseling student, and senior author (DC), who is a GC Program Director, used the GCC to independently code six video-taped genetic counseling sessions of simulated patients, taking notes on the process. After each session, KH and DC compared their checklists and notes, discussed items and concerns, and then made changes to enhance clarity, ensure the measure succinctly captured all major strategies implemented by the genetic counselors, and to address disagreements between raters. This process continued over four months for the remaining five videos. Simultaneously, to evaluate concurrent validity (i.e., how well checklist content correlated with an overall assessment of communication), these video-taped sessions were scored using an overall communication rating ranging from 1 to 5, where 1= poor communication and 5= excellent communication). These overall ratings were then compared to the GCC score for the respective sessions.

To further test inter-rater reliability, a group of four additional second-year GC student raters used the GCC to code one of the six genetic counseling video sessions. They were not provided any in-depth training on how to use the GCC. They were simply told to check off the individual skills on the checklist that they thought were completed during the session and then to score the overall skill categories by summing the number of skills/behaviors checked and selecting the corresponding category rating.

To confirm content validity, DC and KH reviewed results (including codes and themes) from a qualitative study conducted by a genetic counseling student at the University of South Florida. This study consisted of interviews with 19 genetic counselors to assess their GC session goals and elicit communication behaviors and skills they report using during patient sessions to achieve their goals or complete various components of the GC session. Based on these findings a few additional examples were added to further describe several of the skills contained in the GCC and one additional skill was added within the 'Recognizing & Responding to Emotions and Prior Experiences' category.

## RESULTS

### **Final GCC and How to Use It**

The final version of the GCC is a two-page checklist consisting of eight (8) skill categories: Building Rapport, Mutual Agenda Setting & Structuring, Recognizing & Responding to Emotions and Prior Experiences, Educating, Risk Communication, Checking for Understanding, Facilitating Decision Making, and Patient Activating. Each skill category is broken down further into specific skills, with a total of 51 individual skills. To utilize the GCC these skills are checked off as they are completed. Those skills denoted by asterisks (\*) require circling or notes to justify completion, the number of asterisks designates the number of times a type of skill must be utilized for skill completion.

The eight individual skill categories are then classified directly after the session as “None/Few”, “Some”, and “Most/All” according to the number of skills utilized within each category. For example, within “Building Rapport” there are 8 skills; after observing the session if 4 of these skills are completed by the genetic counselor the skill category is classified as “Some”. A small glossary of definitions is included on the final page of the GCC for clarification and reference.

### **GCC Skills Category Descriptions**

*Building Rapport*

The first category within the GCC is “Building Rapport”. We define rapport building as how a provider attempts to connect with their patient and achieve a better understanding of their thoughts, feelings and expectations (Norfolk et al., 2007). It is an integral part of the genetic counseling process, which helps establish a strong working relationship between counselor and patient while also fostering open communication (Veach et al., 2007). As rapport building is a dynamic and fluid process, it can occur throughout GC sessions and is thought to have a positive impact on patient outcomes such as overall satisfaction and adherence (Leach, 2005). Table 1 contains the individual skills used for building rapport contained within the GCC. Several items in this category were taken from Smith’s Patient Centered Communication textbook and the AIDET (acknowledge, introduce, duration, explanation, thank you) framework (Fortin, 2019; Studer Group, 2020).

**Table 1:** Building Rapport Skills of GCC

1	Attend to environment	- <i>Ensure patient is comfortable/feels at ease, minimize noise and visual distractions, place self on same physical level, no physical barriers between, ensure everyone seated, special needs addressed, use translator</i>
2	Greet patient/family	- <i>Identify all people present, verbal greeting, friendly smile, handshake, involve child in pediatric setting, etc.</i>
3	Start off positive	- <i>Thank them for coming in, give them a sincere compliment, apologize if clinic is running late or trouble getting there, small talk, etc.</i>
4	Introduce self and state title/role	- <i>Must do both for skill completion</i>
5	Show respect	- <i>Few interruptions, not hurried, allow patient to share their story, be non-judgmental, ask only one question at a time</i>
6	Employ active listening skills	- <i>Neutral utterances, reflections, summarizing, eye contact, open posture, head nod</i>
7	Use supportive/collaborative language	- <i>e.g., "we" statements, "I am here to support you", establish willingness to work together, etc.</i>

**Table 1 (continued): Building Rapport Skills of GCC**

- |   |   |
|---|---|
| 8 | Facilitate two-way communication with patient   |
|   | - <i>Counselor does not speak more than 90% of session, there is no more than 15-minute sections of the session in which the counselor speaks without eliciting patient involvement</i> |

### *Mutual Agenda Setting and Structuring*

“Mutual Agenda Setting and Structuring” refers to an early part of the patient encounter in which a provider elicits the patient’s concerns, shares what they need to discuss, and together arrive at a shared plan for the visit (Gobat et al., 2015). Agenda setting is often referred to in genetic counseling by the term “contracting”, but ultimately the authors selected the term more common among other healthcare providers (Gobat et al., 2015). Although agenda setting skills typically are used at the beginning of a visit, this category also includes additional behaviors/skills whereby the provider and patient may re-negotiate or modify the agenda or make efforts to structure the visit to ensure the most pressing patient needs are met or the agenda is completed (Table 2). Agenda setting allows providers and patients to collaborate by establishing a shared focus that sets the relational tone for the remainder of the consultation (Gobat et al., 2015). Up front agenda setting has been found to improve time efficiency, improve patient-provider interaction quality, reduce the likelihood of a “doorknob question”, and facilitate patient engagement/involvement in decision making (Brock et al., 2011; Gobat et al., 2015; Rodriguez et al., 2008;). Despite these benefits, research shows physicians are often not utilizing agenda setting (Rey-Bellet et al., 2017).

**Table 2: Mutual Agenda Setting & Structuring Skills of GCC**

- |   |   |
|---|---|
| 1 | Establish mutual understanding of reason(s) for visit                 |
|   | - <i>Overview of purpose, why they came in, referral reason, etc.</i> |



**Table 2 (continued): Mutual Agenda Setting & Structuring Skills of GCC**

2	Determine patient's agenda/goals - <i>Begin with open-ended questions, elicit patient's goals/concerns</i> [Do not check if almost all closed-ended questions]
3	Establish mutual agenda - <i>Laying out what else needs to be discussed, forecasting an overview of visit</i>
4	Encourage patient to ask questions at any point during session; - <i>Give patient permission to interrupt with any questions</i>
5	Follow-through with key agenda items - <i>Redirect patient if needed, use of signposting, most main items are addressed, etc.</i> [If no person's agenda is clear, do not check]
6	Assess patient needs throughout, re-negotiate agenda, flexibility in prioritizing patient's needs - <i>Disclosing test results up front, answering their questions when asked, address patient's immediate concerns before completing provider's agenda</i>

### *Risk Communication*

Risk communication is defined by the World Health Organization as the exchange of information, advice and opinions between experts and people facing threats to their health (WHO, n.d.). Within the genetic counseling profession, risk communication typically includes educating patients of genetic disorders, their personalized genetic risks, and possible risk reducing measures (Fransen, 2006). It also includes a psychosocial assessment of patients' perceptions of risk (Shiloh & Saxe, 1988). This process ultimately prepares the patient for informed decision-making.. Risk communication is therefore a major component of genetic counseling sessions (Bernhardt et al.; 2000; Lobb et al., 2001). Given the challenges in understanding relative risks and odds ratios, recommendations have been made to present both relative risks with absolute risks (Edwards et al., 2001; Noordzij et al., 2017; Schechtman, E. 2002). Some data supports the use of rates over proportions (Grimes, 1999). Additionally, the use of qualitative words such as "low" versus "high" is controversial because it is subjective and may be influenced by prior experiences and expectations (Shiloh & Saxe, 1988). However, how data and risk are presented is expected to have

a significant influence on patient outcomes and therefore it remains important to capture variability (Edwards et al., 2001). Risk communication can be very complex and there are important aspects to achieving patient understanding. According to previous research on risk communication in genetic counseling these can include how the risk itself is presented, how it is framed, and perhaps most importantly, how the individual patient assesses and perceives risk (Fransen et al., 2006; Shiloh & Saxe, 1989). For these reasons a key category included on the GCC is “Risk Communication” with related skills shown in Table 3.

**Table 3:** Risk Communication Skills of GCC

1	Present key risk(s) - Percentages, frequencies, words e.g., "most-likely, low" [Do not check if only relative risk or odds ratios used]
2	Avoid numeracy overload - e.g., select only most important numbers, round to whole number [Gives more #'s only if patient requests]
3	Visual risk presentation used Pie graph, bar graph, pictographs, charts, tables, other
4	Risk framing to reduce bias - Probability of happening; probability of not happening [Both needed to check as complete]
5	Assess/clarify patient risk perceptions if not voluntarily provided by patient - e.g., "how does this number sound to you?" or "I can see it may feel like 100% when so many in your family have cancer but your risk is actually ...." [Check if patient volunteers risk perception]
6	Contextualize risk - Give personalized risk & compare risk to baseline, population or age-related risks (if appropriate)

### *Recognizing & Responding to Emotions and Prior Experiences*

The next category within the checklist concerns counselors’ abilities to recognize patient emotions and previous experiences that may impact decision making or medical care, as well as appropriately respond to them in a way that is beneficial to the genetic counseling experience.

Previous studies have shown that a major focus of genetic counseling sessions is the patient's emotions, whether this is through eliciting their emotional concerns, recognizing an emotion, or responding to patients with empathy (Duric et al., 2003; Lobb et al., 2005). In fact, 'Patient Emotions Make a Difference' is one of the major tenets of the Reciprocal Engagement Model (REM) (Veach et al., 2007). For this reason, the fourth skill category within the GCC is "Recognizing and Responding to Emotions and Prior Experiences" (Table 4). As providers, appropriately recognizing and responding to emotions can help patients better understand and cope effectively with the information they have been given (Pehrson et al., 2016). Furthermore, psychological distress that goes unrecognized and therefore unmanaged, can have significant impact on patient well-being and care (Ryan et al., 2005). Studies suggest using skills such as active listening, recognizing and acknowledging distress, responding to emotional cues and allowing uninterrupted patient talk time can improve patient outcomes (Ryan et al., 2005).

**Table 4:** Recognizing & Responding to Emotions and Prior Experiences Skills of GCC

1	Recognize and acknowledge patient emotions and prior experiences - <i>Use reflections</i> <i>e.g., "that sounds like it was hard"</i>
2	Invite them to share emotions/experiences - <i>Ask how they feel</i> [Check if patient voluntarily expresses emotions or shares experiences]
3	Explore emotions - <i>Explore underlying causes, ask why they feel that way, discuss possible contributing factors</i> [Check if patient volunteers]
4	Provide time/space to process emotions - <i>Allow silence to let patient feel and express thoughts, converse with their partner/family, etc.</i>
5	Provide emotional support - <i>Normalize, express concern, "sorry" or "I wish that...", limit liability, provide tissue, validate, reassure not alone, etc.</i>
6	Stay calm and maintain appropriate affect - <i>Sometimes this involves matching patient affect</i>

## Educating

Patient education is the process in which healthcare providers impart knowledge to their patients regarding their health and medical care options (Nature Research Journal, n.d.). It is a foundation of not only the genetic counseling profession but medicine in general (Marcus, 2014; Veach et al., 2007). In fact, patient education has been listed as a primary factor affecting counselors' selection of content and comprises a significant goal of genetic counseling sessions (Matloff, 1994). Furthermore, it has been found that patients prefer individualized education that is tailored to their unique situation and they retain more information from tailored education than standard interventions (Lauver, 2002; Tluczek et al., 2011). Effective patient education positively impacts quality care and patient safety, while also improving patient satisfaction (Tamura-Lis, 2013). Table 5 lists the Educating Skills included within the GCC to accomplish these goals. Many items within this category are derived from elements of the EDUCATE model (Marcus, 2014).

**Table 5:** Educating Skills of GCC

1	Elicit patient's prior or desired knowledge <ul style="list-style-type: none"><li>- <i>e.g., ask what they already know or want to know, option menu, "tell me what you have heard about..."</i></li></ul> [If counselor uses questions for this, they must be open-ended]
2	Tailor information to patient's needs/wishes/goals/culture/situation <ul style="list-style-type: none"><li>- <i>Ensure personal relevance</i></li></ul> [Do not check if only risk is tailored]
3	Simplify information to reduce cognitive load <ul style="list-style-type: none"><li>- <i>Use plain language, chunking, repetition, structure logically, summarize info, etc.</i></li></ul>
4	Use audio or visual material when educating <ul style="list-style-type: none"><li>- <i>Review pamphlets/printouts, draw things out, or show test results</i></li></ul>
5	Give written material summarizing educational information <ul style="list-style-type: none"><li>- <i>e.g., pamphlets, printouts, patient letters</i></li></ul> [Test results excluded]
6	Eliminate most extraneous details <ul style="list-style-type: none"><li>- <i>Information that is not necessary to achieve session goals</i></li></ul> [Can check if patient asks for the extra details]

## Checking for Understanding

Checking for understanding is how GC's ensure patients comprehend the information discussed during a genetic counseling session and is critical for informed decision making (Henneman et al., 2008). The Genetic Counseling Video Project (GCVP) listed checking for understanding under a function of genetic counseling known as "Activating and Partnering" and found that genetic counselors used paraphrase and interpretation as well as explicitly asking to check client understanding (Roter et al., 2006). Teach-back is a method of directly checking patient understanding by asking patients to repeat in their own words what they have learned (Tamura-Lis, 2013). This method shows great promise in improving quality patient education, safety, and satisfaction (Tamura-Lis, 2013). Teach-back helps providers assure they have covered all necessary information, check for patient comprehension, and provides insight into which aspects of the counseling patients find most pertinent (Tluczek et al., 2011). The "Checking for Understanding" category within the GCC therefore includes teach-back along with other evidence-based methods for assuring patient understanding (Table 6).

**Table 6:** Checking for Understanding Skills of GCC

1	Invite/elicite patient input and thoughts about the information given - e.g., "What are your thoughts about what I just told you?"
2	Use of teach-back or getting patient to summarize information given
3	Explicitly asking what questions patient has about information - NOT "Do you have any questions?" must be open-ended
4	Elicit/discuss how information, condition, or risk impacts or could impact patient's life or family function, etc.

## Facilitating Decision Making

Shared decision making between counselor and patient is fairly universal in genetic counseling sessions (Veach et al., 2007). It is the process by which patients arrive at decisions

regarding their genetic health, and includes decisions such as pursuing genetic testing, informing family members of genetic testing results, or having prophylactic surgeries/surveillance. Decisions made during these sessions can have huge implications for patients and their families. It is therefore critical for patients to make informed decisions with their counselors and healthcare team (Légaré et al., 2016). Shared decision making allows patients and genetic counselors to evaluate available evidence, align goals with possible decisions, and help patients feel supported while considering their options (Andrews et al., 2016; Elwyn et al., 2012). Table 7 lists skills included in facilitating decision making category, many of which come from expert consensus and research such as the Shared Decision-Making model and Three Talk model, as well as the Ottawa Decision Support Framework (ODSF) (Elwyn et al., 2012; Elwyn et al., 2017; Légaré et al., 2006; Ottawa Hospital Research Institute, 2019).

**Table 7:** Facilitating Decision Making Skills of GCC

1	List or ensure patient is aware of all options or actions that can be taken - <i>Including choosing to do nothing</i>
2	Explore possible outcomes of options/actions - <i>Benefits, risks/limitations, probable outcomes of decisions, best case, worst case</i>
3	Use of decision analysis tools - <i>Decision trees, decision guides (e.g., Ottawa Personal Decision Guide)</i>
4	Support patient autonomy - <i>Acknowledge no single right choice, support their choice, explain why patient involvement is needed, involve family members to extent desired, ask permission before giving advice and/or explain reasoning for advice (e.g., standard medical guidelines state...)</i>
5	Help patient clarify and align values with options/actions - <i>Discuss what is most important to patient, point out what fits their values</i>
6	Give scenarios of what others have done and why - <i>Scenarios must include at least 2 options &amp; should not be one-sided</i>
7	Assess readiness to make decision or act and resolve conflict/ambivalence/uncertainty (if any)

## *Patient Activating*

The final skill category included within the GCC is “Patient Activating”. Patient activation refers to a patients' knowledge, skill, and confidence to manage their health, as well as their ability to act upon the decision they have made (Chen et al., 2016). The focus of this category is helping patients act on the shared decision they have made through support and encouragement, as well as helping them adapt to the genetic risk or diagnosis that they face (McAllister et al., 2012). Several of the skills in this category are taken from motivational interviewing as well as coping and support literature (Table 8) (McAllister et al., 2012; Miller & Rose, 2009; Sciacca, 2009)

**Table 8:** Patient Activating Skills of GCC

1	Detail an action plan of next step(s) - <i>Who, what, where, when</i>
2	Explore how to enact action plan/ elicit facilitators - <i>Support, coping mechanisms, existing resources, how dealt with challenge in past, etc.</i>
3	Discuss commitment/barriers to plan - <i>Develop contingency plan, ways to overcome barriers, elicit commitment talk</i>
4	Build confidence - <i>Affirmation, acknowledge patient strengths, thank patient for coming in or effort made during the session</i>
5	Encourage hope - <i>Positive reframing, potential future treatments, ongoing research, use uncertainty to encourage hope, share positive patient stories</i>
6	Provide support resources and/or referrals* - [Also check if resource needs were assessed or offered but patient declined]
7	Invite patient contact - <i>Provide contact information, invite patient to contact with questions, concerns, etc.</i>

A table summarizing the research and literature utilized for justification of each skill category is available for review within the appendices, Table 9: Skill Categories and Corresponding Literature.

## Inter-Rater Reliability

For the first counseling session, the two raters agreed on overall skill category ratings for four of the eight categories. By the last two simulated cases there were no disagreements in category ratings, though variation continued in whether a few skill items were checked. The results of all six sessions are summarized in Table 10.

**Table 10:** Summary of Simulated Patient Video Coding Across Two Raters

	Rater	Session 1 prenatal	Session 2 prenatal	Session 3 cancer	Session 4 cancer	Session 5 prenatal	Session 6 cancer
<b>% of All Skills Agreed<sup>a</sup></b>		50%	87.5%	62.5%	75%	100%	100%
<b>Overall Communication Rating<sup>b</sup></b>	1 2	NA	3.5 3	1 1	4 4	3.5 3	3 2
<b>Skills Category (# items)</b>		<b>Overall Category Classification<sup>c</sup></b>					
<i>Building Rapport (8)</i>	1 2	Some Some	Some Some	None/few Some	Most/all Most/all	Some Some	Some Some
<i>Mutual Agenda Setting &amp; Structuring (6)</i>	1 2	Some None/few	Some Some	None/few Some	Most/all Most/all	Some Some	Some Some
<i>Risk Communication (6)</i>	1 2	Some Some	Most/all Most/all	Some Some	Some Some	Some Some	Some Some
<i>Recognizing &amp; Responding to Emotion and Prior Experiences (6)</i>	1 2	Some Most/all	Some None/Few	Some Some	Most/all Most/all	Most/all Most/all	Some Some
<i>Educating (7)</i>	1 2	Some None/few	Some Some	None/few Some	Most/all Some	Some Some	None/few None/few
<i>Checking for Understanding (4)</i>	1 2	Some Some	Some Some	None/few None/few	Most/all Some	Some Some	None/few None/few
<i>Facilitating Decision Making (7)</i>	1 2	Most/all Some	Most/all Most/all	None/few None/few	Some Some	Some Some	Some Some
<i>Patient Activating (7)</i>	1 2	None/few None/few	None/few None/few	None/few None/few	Some Some	None/few None/few	Some Some

<sup>a</sup> Calculated as the percentage where both raters either checked or did not check the skill as being completed

<sup>b</sup> Ratings on overall communication ranged from 1= poor to 5 = excellent

<sup>c</sup> Category Classifications as: “None/few”, “Some”, or “Most/all”



## Additional Coding- 4 Raters

To determine how others would utilize the checklist, four raters scored one of the prenatal simulated sessions with no training. All four raters agreed in three categories; Building Rapport, Mutual Agenda Setting & Structuring, and Patient Activating. The skill categories where least agreement occurred (where raters were split 50/50) were the Educating and Checking for Understanding categories. The results of this session are summarized in Table 11. Furthermore, students reported the GCC was easy to use and understand, and that having such a checklist was helpful for self-reflection within their patient sessions.

**Table 11:** Results of Secondary Coding of Prenatal Session with Untrained Raters

Categories	# of Skills in Category	How Raters Coded (4 total)		
		None-Few Skills Used	Some Skills Used	Most-All Skills Used
Building Rapport	8	0	4	0
Mutual Agenda Setting & Structuring	6	0	4	0
Risk Communication	6	0	3	1
Recognizing & Responding to Emotion and Prior Experiences	6	1	3	0
Educating	7	2	2	0
Checking for Understanding	4	2	2	0
Facilitating Decision Making	7	0	1	3
Patient Activating	7	4	0	0

## Assessing Content Validity Using Findings from GC Interviews

When comparing data from the other genetic counseling communication study (Zale et al., 2020) to the GCC, it was found that nearly all the reported communication behaviors aligned with skills included within the GCC. However, a few specific examples from the interviews were added to further describe the existing skills. Only 6 behaviors reported by genetic counselors were not

included as skills on the GCC- use of humor, self-disclosure, stay calm, maintain appropriate affect, use of authority, and quizzing. Two of these were combined into a skill and added as, “stay calm and maintain an appropriate affect” as part of the ‘Recognizing & Responding to Emotions and Prior Experiences’ category. The others had been discussed during the process of building the checklist and were purposively excluded. Use of humor was reported by GCs as a method of building rapport and while this can be effective, evidence has also shown it has the potential to backfire and cause emotional/interactional harm (Francis et al., 1999; Saper, 1987). Similarly, GC’s must be careful practicing self-disclosure as although it may help a patient feel the counselor is relatable, it may also be counterproductive to client goal attainment (Paine et al., 2010; Thomas et al., 2006). Use of authority can limit liability or correct misconceptions, but can also emphasize a power difference between counselor and patient, and goes against a core concept of patient-centered care in which the provider transforms their role from one “characterized by authority to one that has the goals of partnership, solidarity, empathy, and collaboration” (Epstein & Street, 2011). Quizzing has been suggested as a strategy for improving comprehension in the past (Geller et al., 1997). However, our research team felt such practices add stress to the patient and the same underlying strategy can be applied through methods such as teach-back without putting the patient on the spot. For these reasons, these reported GC communication skills were excluded from the GCC.

## DISCUSSION

To our knowledge, the GCC is the first process measure specifically designed to assess communication skills of genetic counselors throughout the entirety of a patient session. Where previous measures have focused on one feature of a GC session (i.e. risk communication), the GCC has sought to capture major educational, psychological and social communication tasks (Fransen et al., 2006).

The development of a process measure that is both comprehensive and succinct can be difficult. According to multiple raters within the study, the GCC is not burdensome and becomes even easier to use after becoming familiar with it. Providing comprehensive training to coders on use of the GCC could further improve inter-rater reliability in future studies.

An additional strength of the GCC is that genetic counselors and genetic counseling students found it helpful as a self-reflection and training tool. Although it could be used for educational instruction, this was not the intended purpose of the GCC. Additionally, it is missing the ability to capture information gathering skills and critical thinking skills (e.g., medical and family history taking, risk assessment, etc.) that students must develop. We warn against possible use of the GCC as part of a high stakes assessment of clinical competence because the consequential validity of the GCC has not been assessed. In other words, we have not determined which skills or what number of skills would be necessary for demonstrating clinical competence. Furthermore, although the items were informed by review of healthcare and communication

literature, data are lacking to support which skills positively impact patient outcomes in a genetic counseling setting.

Results suggest the GCC can be used to quantify communication skills and should be applicable in future studies of communication practices in genetic counseling. Further research in this area is pivotal to the advancement of the profession. We anticipate that additional changes will be needed to update the GCC as more inter-rater reliability and validity evidence is accumulated.

Ultimately we hope our study and the GCC will spur more efforts to establish genetic counseling practice standards and give insight into which communication strategies most benefit patient outcomes.

### **Limitations**

The main limitation of the study was that only two primary raters were used to code the majority of the simulated genetic counseling sessions. All raters (DC, KH, and the four GC students) are also from the same university and therefore may share similar biases, thought processes, training, and opinions of what is important during genetic counseling sessions. Additionally, the six simulated patient sessions were only conducted in prenatal and cancer settings and did not include counselors from pediatric or other specialties. Furthermore, we were not able to test the GCC through observation of real-life patient encounters during this research. Therefore, we believe the GCC would benefit from a pilot study of real-life genetic counseling sessions across multiple specialties in the future.

## **Conclusion**

Our research suggests the Genetic Counseling Communication Checklist (GCC) provides a simplified method for measuring communication skills between counselors and their patients. Despite limited training of coders, it achieved adequate inter-rater reliability and its content is validated by current literature and research being conducted in the field. It is our hope that it will eventually be used to provide insight into which communication methods counselors utilize in real-world practice and help future research correlate communication strategies to specific patient outcomes.

## **Conflict of Interest**

No potential conflict of interest was reported by the authors.

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## APPENDICES

## Appendix A: Table 9: Skill Categories and Corresponding Literature

Skill Category	Literature Validating Inclusion
Building Rapport	Leach, 2005; Norfolk et al., 2007; Veach et al., 2007
Mutual Agenda Setting & Structuring	Brock et al., 2011; Gobat et al., 2015; Rey-Bellet et al., 2017; Rodriguez et al., 2008
Risk Communication	Bernhardt et al., 2000; Edwards et al., 2001; Fransen et al., 2006; Grimes, 1999; Lobb et al., 2001; Noordzij et al., 2017; Schechtman, 2002; Shiloh & Saxe, 1988; Veach et al., 2007
Recognizing & Responding to Emotion and Prior Experiences	Duric et al., 2003; Lobb et al., 2005; Pehrson et al., 2016; Ryan et al., 2005; Veach et al., 2007
Educating	Lauver, 2002; Marcus, 2014; Matloff, 1994; Tamura-Lis, 2013; Tluczek et al., 2011; Veach et al., 2007
Checking for Understanding	Henneman et al., 2008; Roter et al., 2006; Tamura-Lis, 2013; Tluczek et al., 2011
Facilitating Decision Making	Andrews et al., 2016; Elwyn et al., 2012; Elwyn et al., 2017; Légaré et al., 2006; Légaré et al., 2016; Ottawa Hospital Research Institute, 2019; Veach et al., 2007
Patient Activating	Chiauzzi et al., 2016; McAllister et al., 2012; Miller & Rose, 2009; Sciacca, 2009



## Appendix B: The Genetic Counseling Communication Checklist:

Genetic Counseling Communication Checklist							
Setting: Cancer; Prenatal; Pediatric; Other	Case Number:						
Skills categories are in bold below and highlighted in gray - NOTE: Number of skills checked off in each category will be totaled at the end				None-Few:	Some:	Most-All:	N/A
Building Rapport	X	N/A		0 to 2	3 to 5	6 to 8	
1. Attend to environment ( <i>ensure patient is comfortable/feels at ease, minimize noise and visual distractions, place self on same physical level, no physical barriers between, ensure everyone seated, special needs addressed, use translator</i> )***			Notes:				
2. Greet patient/family ( <i>identify all people present, verbal greeting, friendly smile, handshake, involve child in pediatric setting, etc.</i> )**							
3. Start off positive ( <i>thank them for coming in, give them a sincere compliment, apologize if clinic is running late or trouble getting there, small talk, etc.</i> )*							
4. Introduce self and state title/role** [must do both for skill completion]							
5. Show respect ( <i>few interruptions, not hurried, allow pt. to share their story, be non-judgmental, ask only one question at a time</i> )**							
6. Employ active listening skills ( <i>neutral utterances, reflections, summarizing, eye contact, open posture, head nod</i> )***							
7. Use supportive/collaborative language ( <i>e.g., "we" statements, "I am here to support you", establish willingness to work together, etc.</i> )							
8. Facilitate two-way communication with patient ( <i>counselor does not speak more than 90% of session, there is no more than 15-minute sections of the session in which the counselor speaks without eliciting patient involvement</i> )							
Mutual Agenda Setting and Structuring	X	N/A		0 to 2	3 to 4	5 to 6	
1. Establish mutual understanding of reason(s) for visit ( <i>overview of purpose, why they came in, referral reason, etc.</i> )			Notes:				
2. Determine patient's agenda/goals ( <i>begin w/ open-ended questions, elicit goals/concerns</i> ) [Do not check if almost all closed-ended questions]							
3. Establish mutual agenda ( <i>laying out what else needs to be discussed, forecasting an overview of visit</i> )							
4. Encourage patient to ask questions at any point during session; give them permission to interrupt with any questions							
5. Follow-through with key agenda items ( <i>redirect patient if needed, signposting, most main items are addressed, etc.</i> ) [If no person's agenda is clear, do not check]							
6. Assess patient needs throughout, re-negotiate agenda, flexibility in prioritizing patient's needs ( <i>disclosing test results up front, answering their questions when asked, address patient's immediate concerns before completing provider's agenda</i> )							
Risk Communication	X	X	N/A	0 to 2	3 to 4	5 to 6	

Choose up to 2: patient chance of gene mutation, risks of showing symptoms, risks of procedures, family risks/inheritance, other _____	1	2				
1. Present key risk(s) ( <i>percentages, frequencies, words e.g., "most-likely, low"</i> )* [Do not check if only relative risk or odds ratios used]				Notes:		
2. Avoid numeracy overload (e.g., <i>select only most important numbers, round to whole numbers</i> ) [Gives more #'s only if patient requests]						
3. Visual risk presentation used (pie graph, bar graph, pictographs, charts, tables, other _____)*						
4. Risk framing to reduce bias ( <i>probability of happening; probability of not happening</i> ) [Both needed to check as complete]**						
5. Assess/clarify patient risk perceptions if not voluntarily provided by patient (e.g., <i>"how does this number sound to you?"; "I can see it may feel like 100% when so many in your family have cancer but your risk is actually ...."</i> ) [Check if patient volunteers risk perception]						
6. Contextualize risk (Give personalized risk & compare risk to baseline, population or age-related risks (if appropriate))						
<b>Recognizing &amp; Responding to Emotions and Prior Experiences</b>	X	N/A		0 to 2	3 to 4	5 to 6
1. Recognize and acknowledge patient emotions and prior experiences ( <i>use reflections e.g., "that sounds like it was hard"</i> )				Notes:		
2. Invite them to share emotions/experiences ( <i>ask how they feel</i> ) [check if patient voluntarily expresses emotions or shares experiences]						
3. Explore emotions ( <i>explore underlying causes, ask why they feel that way, discuss possible contributing factors</i> ) [check if patient volunteers]						
4. Provide time/space to process emotions ( <i>allow silence to let patient feel and express thoughts, converse with their partner/family, etc.</i> )						
5. Provide emotional support ( <i>normalize, express concern, sorry or I wish that..., limit liability, provide tissue, validate, reassure not alone, etc.</i> )*						
6. Stay calm and maintain appropriate affect ( <i>sometimes this involves matching patient affect</i> )						
<b>Educating (Not including risk)</b>	X	N/A		0 to 2	3 to 5	6 to 7
1. Elicit patient's prior or desired knowledge (e.g., <i>ask what they already know or want to know, option menu, "tell me what you have heard about..."</i> ) [If counselor uses questions for this they must be open-ended]				Notes:		
2. Tailor information to patient's needs/wishes/goals/culture/situation ( <i>ensure personal relevance</i> ) [Do not check if only risk is tailored]						

3. Simplify information to reduce cognitive load ( <i>use plain language, chunking, repetition, structure logically, summarize info, etc.</i> ) ***							
4. Use audio or visual material when educating ( <i>review pamphlets/printouts, draw things out, or show test results</i> )*							
5. Give written material summarizing educational information (e.g., <i>pamphlets, printouts, patient letters</i> ) [Test results excluded]							
6. Eliminate most extraneous details ( <i>information that is not necessary to achieve session goals</i> ) [Can check if patient asks for the extra details]							
7. Clearly lay out 3 to 5 key messages ( <i>concise, start with and/or end with key points</i> )[Do not check if key information is missing or insufficient information is given]							
i. ii. iii. iv. v.							
<b>Checking for Understanding</b>	X	N/A		0 to 1	2 to 3	4	
1. Invite/elicite patient input and thoughts about the information given (e.g., " <i>What are your thoughts about what I just told you?</i> ")				Notes:			
2. Use of teach-back or getting patient to summarize information given							
3. Explicitly asking what questions patient has about information [ <i>NOT "Do you have any questions?"-must be open-ended</i> ]							
4. Elicit/discuss how information, condition, or risk impacts or could impact patient's life or family function, etc.							
<b>Facilitating Decision Making</b>	X	X	N/A	0 to 2	3 to 5	6 to 7	
Choose up to 2 key decisions: have genetic testing, continue pregnancy, healthcare follow-up, discuss risks with family, other _____	1	2		Notes:			
1. List or ensure patient is aware of options or actions that can be taken ( <i>including choosing to do nothing</i> )							
2. Explore possible outcomes of options/actions ( <i>benefits, risks/limitations, probable outcomes of decisions, best case, worst case</i> )***							
3. Use of decision analysis tools ( <i>decision trees, decision guides ( e.g., Ottawa Personal Decision Guide)</i> )							
4. Support patient autonomy ( <i>acknowledge no single right choice, support their choice, explain why patient involvement is needed, involve family members to extent desired, ask permission before giving advice and/or explain reasoning for advice (e.g., standard medical guidelines state...)</i> )							
5. Help patient clarify and align values with options/actions ( <i>discuss what is most important to patient, point out what fits their values</i> )							
6. Give scenarios of what others have done and why ( <i>scenarios must include at least 2 options &amp; should not be one-sided</i> )							
7. Assess readiness to make decision or take action and resolve conflict/ambivalence/uncertainty (if any)							

Patient Activating	X	N/A		0 to 2	3 to 5	6 to 7	
1. Detail an action plan of next step(s) ( <i>who, what, where, when</i> )***			Notes:				
2. Explore how to enact action plan / elicit facilitators ( <i>support, coping mechanisms, existing resources, how dealt with challenge in past, etc.</i> )*							
3. Discuss commitment/barriers to plan ( <i>develop contingency plan, ways to overcome barriers, elicit commitment talk</i> )*							
4. Build confidence ( <i>affirmation, acknowledge patient strengths, thank patient for coming in or effort made during the session</i> )**							
5. Encourage hope ( <i>positive reframing, potential future treatments, ongoing research, use uncertainty to encourage hope, share positive patient stories</i> )							
6. Provide support resources and/or referrals* [also check if resource needs were assessed or offered but patient declined] (_____)							
7. Invite patient contact ( <i>provide contact information, invite patient to contact with questions, concerns, etc.</i> )							
Additional Communication Skills Used but Not Listed: [See separate form for gathering of family and medical information]							
1.							
2.							
3.							

\* Notes or circling necessary to justify completion

\*\* Two skill examples needed to justify completion

\*\*\* Three or more skill examples needed to justify completion (use one multiple times or use multiple different examples)

**To complete please circle the number of items checked for each domain to categorize numbers of skills used in each category (gray rows)**

N/A Not applicable. A skill domain should be marked at "N/A" if 50% or more of the skills within its category are N/A

## Appendix C: Glossary Included on GCC

- Validating/Legitimizing- recognizing or affirming the worth of the patient's feelings or opinions "understandable that"; "I can see how"; " It's ok to be mad"
- Limiting liability- ensuring patient understands this is not their fault (or at least not ALL their fault), there is nothing they could have done or not done differently to prevent this
- Sorry that or I wish that - "I'm sorry that you had such a bad experience"; "I wish you didn't have to deal with this"
- Normalization- reassuring patient how they are feeling or their reactions are normal or common among other people "Lots of people feel..."
- Positive reframing- express concept, experience, or plan positively; e.g. "now we know risk, there is something we can do about it"; "we don't want to deny how hard it is but it also led to\_\_\_ which is a good thing"

## **ABOUT THE AUTHOR**

Katherine Neuer Hehmeyer graduated from the University of Central Florida with a bachelor's degree in Molecular and Microbiology as a member of UCF's Burnett Honors College in 2014. While an undergraduate, Katherine volunteered at Winnie Palmer Hospital for Women and Babies on the Mother Baby floor and in Triage. After graduating she worked full-time as a Certified Nursing Assistant in the emergency room at Winnie Palmer and pursued her interest in genetic counseling by volunteering at the Center for Maternal Fetal Medicine with the prenatal genetic counselors. She was offered their Genetic Counseling Assistant position and worked with them until becoming a student at the University of South Florida in August of 2018. She is currently in her second year and will graduate with her Master of Science in Public Health with a concentration in Genetic Counseling degree in May of 2020.