EVALUATION OF COMMUNICATION SKILLS IN GENETIC COUNSELING TRAINING PROGRAMS: A NEEDS ASSESSMENT

by

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ABSTRACT

Communication skills are a necessary part of training and education for medical professionals and a key element of genetic counseling practice. These skills include both educating patients and addressing psychosocial needs. Although the types of communication that genetic counselors should master have been expressed in the literature, significantly less is known about effective ways to assess communication skills. This study was designed as a needs assessment to gain an understanding of how communication skills are currently being assessed in genetic counseling programs across the United States and Canada and to evaluate if a new communication assessment tool would be beneficial to these programs. Semi-structured phone interviews were conducted with directors of 14 of the 35 accredited programs and thematic analysis was performed on the notes generated from the interviews. It was discovered that all of the programs assess communication skills in some way, but no program uses the exact same methods. Most of the evaluation methods used in genetic counseling programs are not based on relevant literature or a known theoretical framework. Program directors are mostly interested in the creation of a new assessment tool, which may improve students' communication skills and assist supervisors in identifying and addressing deficiencies. This study has public health significance because good communication contributes to better patient satisfaction, more teamwork within the medical

team, better patient compliance, more cost-effective medicine, and better health in general. Assessing communication skills effectively would better ensure that genetic counselors are competent in the necessary skills when they complete their training.

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PREFACE

I owe infinite thanks to so many individuals for their support throughout my graduate program and thesis research. First and foremost, to my committee, who kept me on track with deadlines, read my document, encouraged me, and gave invaluable feedback. Robin Grubs, Doug White, Martha Terry, and Candy Kammerer – thank you so much! You are my role models, and I can only hope to achieve your knowledge, eloquence, and work ethic during my own professional journey.

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1.0 INTRODUCTION

1.1 DESCRIPTION OF THE PROBLEM AND SPECIFIC AIMS

Communication skills are a necessary part of training and education for medical and public health professionals. These skills have been taught in various ways by programs around the United States, including the use of actors for role play, lectures, and clinical experience. In genetic counseling, books like *Facilitating the Genetic Counseling Process: A Practice Manual* are used by students and educators to work on the development of such skills.[1] Once complex communication skills are taught, it can often be difficult to assess these skills as students begin to use them within their training. In this project, we seek to understand how current genetic counseling programs assess students' communication skills. We will then describe a novel intervention fidelity monitoring (IFM) strategy for a complex behavioral intervention, which in the future could be translated into an assessment tool for the genetic counseling community.

Genetic counseling is a field that is quickly growing, and there is currently an unprecedented amount of interest in developing new training programs across the United States. As more and more programs are set up and more trainees learn genetic counseling, the importance of consistency in training and high standards only increases. Compiling information on how programs currently assess communication skills will allow us to understand and improve upon such assessment.

The intervention fidelity monitoring (IFM) strategy described is one developed and used in Dr. Douglas B. White's Family Support Intervention in Intensive Care Units, or "Four Supports" research study.[2] This is an intervention to improve surrogate decision-making for critically ill adults. Interventionists act as palliative/critical care team members and are solely focused on the psychosocial support of caregivers who have loved ones at the hospital in intensive care.[2] "Four Supports" refers to the four types of support that the interventionist is meant to provide the surrogate in coordination with the clinical team: emotional support, communication support, non-directive decision support, and anticipatory grief support.[2] Interventionist interactions with surrogates are audio-recorded, and these audio recordings are audited by trained researchers to assess how well complex communication skills were used and how well the interventionists adhered to the research protocol.

The four types of support used in the "Four Supports" study are key principles in genetic counseling as well. Therefore, the intervention fidelity monitoring tool utilized in the study could easily be adapted to fit into the genetic counseling environment. Assessing how well one supports a patient and utilizes complex communication skills can be difficult. Developing a standard procedure for this type of assessment would allow genetic counseling trainees to receive concrete, specific, and consistent feedback about how to improve these skills.

To achieve our goals of exploring how communication skills are currently assessed and if development of a new evaluation tool would be useful, two specific aims were targeted, as discussed below. Using these specific aims, we illustrate an IFM strategy for future behavioral interventions as well as provide a strategy for genetic counseling assessment. Methods included interviewing program directors by phone to understand current assessment strategies. This

interdisciplinary project seeks to fulfill a public health need for assessment tools that will improve complex communication skills, therefore improving the quality of patient interactions.

1.1.1 Specific Aim 1

Perform a needs assessment of how genetic counseling programs currently assess communication skills.

1.1.2 Specific Aim 2

Describe a novel IFM strategy for a complex behavioral intervention that was developed and used for Dr. Doug White's "Four Supports" research study and discuss how this could be used in the future to develop a communication assessment tool for genetic counseling.

1.2 COMMUNICATION SKILLS IN MEDICINE

There is no lack of literature discussing the importance of communication in medicine. It is generally accepted that the ability to communicate well is a key component of effective medicine. Good communication is a vital element contributing to better patient satisfaction, increased teamwork within the medical team, better patient compliance, more cost-effective medicine, less physician burnout, and better health in general.[3–8]

Communication is a broad term, and often knowing what constitutes high quality doctor-patient communication depends on the definition used, or the most important elements.[9] A 1999

medical conference sponsored by the Bayer Institute for Health Care Communication and the Fetzer Institute described seven key elements of communication between doctors and their patients.[10] These elements are "(1) build the doctor–patient relationship; (2) open the discussion; (3) gather information; (4) understand the patient's perspective; (5) share information; (6) reach agreement on problems and plans; and (7) provide closure."[10] In order to complete these goals successfully, professionals must use complex verbal and nonverbal communication skills which should be taught and assessed effectively during medical training programs.[9]

Communication helps a doctor to manage patient uncertainty and prepare patients for what is or could be ahead in their lives.[11] Mishel (1988) describes uncertainty as the "inability to determine the meaning of illness-related events."[12] When doctors communicate well with their patients and help manage uncertainty, patients can accept diagnoses and feel ready for prognoses and possible future symptoms.[11] For severe illness, this can include bereavement. Therefore, limited or poor communication increases stress.[13] To be truly prepared for complex and potentially devastating conditions, patients and family members need to be able to process both cognitively and emotionally.[11] The ability to process information requires education from a physician, but also complex psychosocial communication skills that are centered around the patient's values.[11,14]

Significant literature focuses on communication skills in palliative care because of the intense emotion involved in end-of-life situations.[15] Though the data are often specific to death and dying, patients with complex conditions and in intense emotional states related to these conditions may have similar reactions, needs, and values. In end-of-life care, caregivers have expressed that communication about a patient's death and dying is one of the most neglected aspects by physicians and is often inadequate.[11,14] Those who do not receive accurate and

realistic information about life expectancy are more likely to make decisions that they regret later on.[16] Although hope is important for patients and caregivers in these difficult situations, false hope can change a patient's decision-making process, and doctors and their patients may exhibit discordant expectations about prognosis.[17] Therefore, a balance between hope and honesty is complex but imperative for physicians working with such patients.[18]

Doctors should try to strive for cultural competency in order to improve communication.[7] Doctor-patient communication has been found to differ depending on a patient's background. In general, communication is significantly poorer quality in patients who are African American, Asian, or Hispanic than those who are Caucasian.[19–21] Health disparities have the potential to grow if doctors do not consider a patients background, whether it is cultural, educational, or socioeconomic. Research shows that patients with lower educational backgrounds are involved in fewer medical decisions.[3,22] Patients with lower educational backgrounds may also have different preferences and different definitions of physician quality of care.[3] Residents have also been found to overestimate the health literacy of their patients.[23]

Communication also takes on a new complexity in the modern era, as telemedicine becomes more prominent. Some telemedicine interactions include a video-feed, but telephone discussions lack any visual tool which eliminates the use of nonverbal skills.[24] Patients have described problems with telemedicine when the medical professional fails to listen to the caller, ask enough questions, or discuss the relevant issues concerning the patient's health concern.[24] Learning the nuances of this communication process may become more necessary in training programs, so medical professionals can provide the same quality of healthcare to patients receiving this type of care.

Many steps still need to be taken in order to fully understand how to best communicate with patients. Research indicates that patients often are unsatisfied with their doctors' communication skills. There can also be discordance between patient or caregiver and doctor understanding of an illness and its prognosis. Patients are often significantly more optimistic than their doctors, and therefore display false hope.[16] Doctors are also often unsatisfied with their encounters with patients.[25] In an age of electronic medical charts and medical information sent to patients via the computer, doctors still say that they need to be able to talk to patients and ensure understanding. Spending the time needed with every patient can be difficult, but primary care physicians have expressed a need for in-depth communication, especially at discharge when care is transitioned and there is a risk for adverse events.[25] Considering the negative health effects that may be caused by poor physician communication, there is an urgent need for quality patient-physician communication to be taught and practiced. Without basic knowledge of the components of effective communication, teaching and assessing communication skills is challenging.[6]

1.2.1 Teaching Communication Skills

The Accreditation Council for Graduate Medical Education (ACGME) has listed interpersonal and communication skills as one of its six core competencies, along with patient care, medical knowledge, practice-based learning and improvement, professionalism, and systems-based practice.[26] When trained in communication, medical students and residents are better prepared to handle difficult patient encounters and provide better quality healthcare.[7,8,14] For practicing doctors, receiving both frequent feedback and communication training (instead of feedback alone) increases behaviors embedded in patient-centered counseling.[27,28]

Some literature describes specific tools to help medical students with communication. One example is of a tool is that of behavior change techniques used to help patients avoid lifestyle-related illnesses.[29,30] Creating specific tools to help students facilitate these techniques can promote consistency within behavior change education.[29] It may also improve doctors' confidence in their interactions with patients and preparedness for situations that are described in communication tools.[29] Other well-known models for communication or giving bad news include the SPIKES model: Setting, Perception, Invitation, Knowledge, and Emotion.[14] Also the NURSE model for empathic verbal skills: Naming, Understanding, Respecting, Supporting, and Exploring.[14] Some models may seem simple or intuitive, but these strategies to remember how to treat a patient and discuss difficult topics may provide doctors with the foundation for developing more complex communication skills.

The expansion of healthcare fields has allowed for specific professions and specialties that are "person-oriented" to grow.[5] These fields, which have been listed as specialties like psychiatry, pediatrics, and obstetrics/gynecology, are in contrast with "technique-oriented" fields like surgery and emergency medicine (in which communication skills are still an important element).[5] When medical students were matched into person-oriented versus technique oriented specialties, there was no significant difference between the scored quality of their communication skills.[5] The researchers who studied this still asked the question: Should "some specialties be held to a higher standard for certain communication skills? Should there be certain types of communication skills that are expected for some specialties but not others?"[5]

Students recognize that it is stressful and demanding to practice communication with patients, especially when discussing serious illness.[15] Medical students have expressed that one barrier to learning the more complex and difficult skills, particularly in end-of-life care, is

gatekeeping by medical professionals.[31] When complex conversations with patients and caregivers arise, research suggests that professionals may have these conversations themselves and block student access to attempting them.[31] Students also feel unsupported when they do not have the opportunity to discuss and debrief a patient interaction with their supervisors.[31]

Most programs that teach communication skills focus heavily on providing patients and families with information, indicating that there is a need for more emphasis on preparing individuals emotionally for prognoses.[11] When medical and residency programs feel that communication skills have not had enough emphasis in the program, often workshops focusing on these skills are suggested, facilitated, and studied.[7,8,14,32] Workshops allow trainees to hone in on their communication skills and to consider their current knowledge and potential deficiencies. Many students initially overestimate their skills until they spend the time considering and working on communication specifically.[7] Though workshops are helpful because of their specific focus, they can be difficult to organize.[7] Because communication skills are a critical competency for medical education, there is an urgent need to include effective training within programs' curricula.

Due to time constraints in a medical training program to learn and discuss the myriad of competencies that must be mastered, web-based communication training has also been suggested and studied.[33] With the advancement of technology, online tools can assess the acquisition of skills through role plays in which language production is transcribed and analyzed using a system that can quantify behaviors.[33] Such tools may be an effective supplement to the skills that are learned in the physical classroom and in observations and patient interactions.

Although many studies discuss the importance of training physicians to communicate, fewer have focused specifically on the efficacy of communication skills training for physicians.[14]

It is therefore difficult to pinpoint which teaching methods are most effective. Still, hypotheses have been made. For example, Back et al. (2009) suggest that "rather than focusing on teachers as knowledge ATMs from which learners make passive withdrawals, we make the learner's effort, discovery, and feedback the primary educational experience."[34] Just as the medical community discusses the need to shift from information-giving to psychosocial support, this theory pushes supervisors to do the same when training students.

1.2.2 Assessing Communication Skills

Communication skill assessment provides medical programs with a way to gather evidence of students' attainment of skills presented to them in their training and required of them as physicians.[4] The rigorous and effective assessment of these skills is therefore a necessity.[6]

Since patient-centered communication is effective, and each individual's values must be taken into account in order to use complex communication skills effectively, it is difficult to consider general guidelines for what communication style is good or poor quality.[35] Similarly situated patients may react differently to the same communication technique. Adapting to an individual's needs or unique qualities is considered part of the "art of medicine."[35] Because of this, using the same communication style or skill at a different time or in a slightly different manner can have vastly different effects on patients. Smiling at a patient while building rapport can make one individual feel a doctor's kindness and warmth, but smiling while describing something painful could be insulting or disingenuous.[6] Understanding these subtleties and knowing the best way to approach each individual patient is the complexity of this art.

When medical schools in the United Kingdom were surveyed, challenges in the assessment of communication skills included defining levels of competence at different points in

a student's training, lack of resources, robustness and validity of assessments, consistency across evaluators, and the ability to integrate the medical process and the communication process.[4] It is also difficult to evaluate the quality of medical care based on complex communication skills because details regarding the outcomes of interpersonal communication are not always readily available in medical records.[35] Unlike quantitatively tracking a patient's vital signs for improvement that would imply quality technical care, a patient's emotional journey and interpersonal discussions are often not recorded or tracked with the same detail. The lack of qualitative data in a medical chart may limit the ability to record a physician's communication quality.

Standardized or simulated patients have been described many times in the literature and are often used in medical training program.[6,36–39] Therefore, they have become widely accepted as a staple form of clinical assessment in medical schools. Patient interactions including diagnosis, symptoms, behaviors, and emotional concerns are created and professional actors portray the patients with whom students practice their clinical skills. These simulations are often video-taped for further assessment as well as the opportunity for self-reflection.[6,15] Although the use of standardized patients is widely accepted, the use of a specific type of evaluation and the effectiveness of the evaluation have been much less studied. Results of several studies indicate that when qualitative feedback supplements quantitative evaluation, such as using a Likert scale to assess specific skills and goals of a patient session, students agree with and accept the feedback to a higher degree.[6] Standardized patients evaluated the students as well, using the Likert scale to evaluate the degree to which "the doctor made me feel comfortable" and "the doctor's explanation was easy to understand."[6] The subjectivity of answering these questions has been recognized as one of the most significant barriers of standardized patients.[6] The only

proposed solution to this is the use of multiple raters, in hopes of high inter-rater reliability.[6,40] Some studies of standardized patients have shown poor inter-rater reliability when multiple raters are used, and it is important to find assessment tools that will increase consistency, especially in skills that increase both patient satisfaction and patient understanding.[37]

One of the most commonly used assessments is an exam: the Objective Structured Clinical Exam (OSCE).[4,40,41] This exam was originally described as "a timed examination in which medical students interact with a series of simulated patients in stations that may involve history-taking, physical examination, counselling or patient management."[38] Just as simulated patients have been described in the literature as a useful teaching tool, they are also useful in assessment. Evaluators can directly observe how a student would deal with specific medical and psychosocial situations and assess the skills used. Criteria for evaluation are predetermined, and all students can be evaluated on the same patient scenario.[37,38] The value of the OSCE specifically is that it also has been extensively studied and found reliable throughout its years of use (since 1975).[40] The OSCE still has disadvantages, which include the significant cost to facilitate the exams, the organizational effort in planning and carrying out the exam, and that standardized scenarios may never be able to fully mimic real life.[14,39,40] Laidlaw et al. (2014) described the gold standard of such assessment as one that evaluates all aspects of communication on a day-to-day basis.[4] A one-time exam can assess how a student performs in that situation and at that point in his or her training, but it is not a repeated assessment so it cannot reflect improvement or correction of deficiencies.

Not every OSCE is the same, some being formative and others summative, and therefore different rating scales have been created and employed.[9] The variability in these exams and assessments allows for medical schools to pick and choose depending on the purpose of the

OSCE they would like to use, but it does not eliminate the need for a standardized assessment method that is known to be effective. When psychometric rating scales from OSCEs were reviewed using the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) checklist, flaws in their methodological quality were found.[9] The COSMIN checklist includes boxes for internal consistency, reliability, measurement error, content validity, construct validity, criterion validity, and responsiveness.[42] As an addition to the checklist, each box can then be scored as excellent, good, fair, and poor quality, for which specific criteria are described.[42] If various assessment tools or rating scales continue to be created and are not validated in theory and found effective, how can medical educators ensure that students are graduating from medical schools with the high quality of communication skills that is required to be successful doctors and to improve the health of patients?

Peer evaluation is also an effective tool that can benefit both the evaluator and the one being evaluated.[43] Despite concerns that peers may be biased, their evaluations have been found to correlate with teacher ratings, and they may provide additional opportunities for assessment and improvement.[43] Peer evaluation during medical training can also promote this practice in the professional setting and prepare doctors to be evaluated critically by other medical professionals.[43] This process may in turn provide students with a first look into supervisor training, so they could become interested in teaching students in the future. Beyond peer assessment is the skill of being able to assess one's own communication skills, which is always important for consistent reflection of one's strengths and weaknesses during every patient encounter.[44] Self-assessment tools have been created to help individuals guide this reflection and remind them of the most important elements of a session.[24]

While considering improvements and needs for assessment in training programs, it is important to recognize an observation made by George Miller: "no single assessment method can provide all the data required for judgment of anything so complex as the delivery of professional services by a successful physician."[45] Multiple types of assessment at multiple points during a training program could strengthen the feedback students receive and provide students multiple ways to think about improving their communication skills.

1.3 COMMUNICATION SKILLS IN COUNSELING PROFESSIONS

As healthcare continues to increase in complexity with the branching out of many different specialties and professions, the coming together of all professions to ensure high standards for education of students in all specialties of healthcare (medicine, nursing, physician assistantship, etc.) has become more critical. Team-based education in schools for the health professions has become a recognized need.[46,47] "Core Competencies for Interprofessional Collaborative Practice" were therefore created by a panel of various healthcare professionals. The four core competencies include interprofessional communication, which emphasizes the ability to "communicate with patients, families, communities, and other health professionals in a responsive and responsible manner that supports a team approach to the maintenance of health and the treatment of disease."[46]

When exploring how communication skills are studied in person-oriented fields like psychology and social work, little relevant literature was available, especially compared to the extensive research and published papers regarding communication in medicine. Research does suggest that social work interventions are effective in addressing and supporting a patient's

psychosocial needs.[48,49] These professions, as well as genetic counseling, mainly differ from medical interactions because the main goal of specialists is to provide information and support, instead of directly providing treatments.[50] Therefore, different communication skills and assessments may be necessary to focus on the specific goals of professions that place such emphasis on psychosocial skills.

1.4 GENETIC COUNSELING

The National Society of Genetic Counselors (NSGC) defines genetic counseling as "the process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease."[51] The definition goes on to explain that "this process integrates the following: Interpretation of family and medical histories to assess the chance of disease occurrence or recurrence. Education about inheritance, testing, management, prevention, resources and research. Counseling to promote informed choices and adaptation to the risk or condition."[51] Genetic counseling is a relatively new profession and has therefore been studied less, but the importance of good communication training, assessment, and execution is apparent in the definition alone and has been discussed in the literature.[52]

The master's degree in genetic counseling was created to train individuals to convey genetic information to patients as well as to address psychosocial needs, and genetic counseling has been described in the literature as a "communication process."[53] Due to the limited time of the two-year degree required to become a genetic counselor, some literature has suggested that psychosocial training may not receive as much focus as training in patient education and genetics information, and therefore genetic counselors spend the majority of patient interactions on

education.[28,53,54] As the genetic counseling field has grown, strategies to incorporate psychosocial communication have been embedded in the literature and textbooks. Though some skills are similar to those needed for medical professionals, genetic counseling is a separate field with its own specific set of skills and goals. Communication skills that textbooks focus on include attending, empathy, responding to client cues and affect, information gathering, contracting, facilitating the decision-making process, multicultural counseling, and recognizing one's own limits.[1,55]

1.4.1 Genetic Counseling Practice-Based Competencies

All accredited genetic counseling graduate programs are required to provide evidence of competence in clinical communication among their students. The Accreditation Council for Genetic Counseling (ACGC) develops and oversees extensive accreditation standards for genetic counseling training programs from sponsorship to operational policies to program evaluation to curriculum.[56] Although communication skills are alluded to within the ACGC content areas of instruction, this information is somewhat vague. It is mostly implied in sections like psychosocial content, which includes interviewing techniques, dynamics of grief and bereavement, multicultural sensitivity and competency, and crisis intervention.[56]

The ACGC is also responsible for overseeing the practice-based competencies that all students are expected to master before leaving the program.[57] These competencies are categorized into four domains: genetics expertise and analysis; interpersonal, psychosocial and counseling skills; education; and professional development and practice.[58] Communication skills are embedded in all of these domains, though the majority of competencies regarding communication are within the psychosocial and counseling skills domain. To list all of the

competencies that fall into the category of communication would be quoting a large portion of the competencies document, but some notable competencies include “employ active listening and interviewing skills to identify, assess, and empathically respond to stated and emerging concerns” and “promote client-centered, informed, non-coercive, and value-based decision-making.”[58]

The competencies address assessment as well, though not nearly in as much detail. These are listed below:

- “Effectively give a presentation on genetics, genomics, and genetic counseling issues.”[58] An example provided under this competency is to “assess one’s own teaching style and use feedback and other outcome data to refine future educational encounters.”[58]
- “Demonstrate a self-reflective, evidenced-based and current approach to genetic counseling practice.”[58] An example provided under this competency is to “seek feedback and respond appropriately to performance technique.”[58]
- “Understand the methods, roles and responsibilities of the process of clinical supervision of trainees.”[58] An example provided under this competency is to “engage in active reflection of one’s own clinical supervision experiences.”[58]

There is no other governing document within the practice of genetic counseling that requires specific types, frequencies, or qualities of communication skill assessment.

1.4.1.1 Assessment of Communication Skills in Genetic Counseling

Biesecker (2010) explains that “how well genetic counselling meets clients’ needs in enhancing quality of life is determined by the expert skills of counsellors to assist clients in using their own psychosocial assets to adapt to their circumstances.”[52] It is therefore important that genetic

counseling students complete their training with these "expert skills," and that their proficiency in such skills is adequately assessed.

There is a gap in the literature when it comes to studies on the assessment of communication skills in genetic counseling. Textbooks in genetic counseling, like *Facilitating the Genetic Counseling Process: A Practice Manual* do discuss strategies to give and receive effective feedback. These strategies encompass how to express negative critiques and how to clarify and accept feedback that one receives.[1] Another textbook used in training programs, *A Guide to Genetic Counseling*, includes a chapter entitled "Student Supervision: Strategies for Providing Direction, Guidance, and Support."[55] This includes suggestions for how to approach informal feedback and an example of an assessment to be used for patients to express their satisfaction with a student's counseling. A specific evaluation form for supervisors to fill out is not suggested. These textbooks include detailed descriptions of communication skills and are used as an effective teaching tool. Lacking in these resources are specific forms and methods to assess the skills that are described and to identify any deficiencies.

Just as simulated patients are used in medical training, they have been proven to be effective teaching tools for genetic counseling students and more realistic than role-playing patient situations with classmates or colleagues.[59] Despite use of standardized patient encounters, research revealed that experienced genetic counselors have variation in their communication styles.[54] This is reflected in the philosophies of both teaching and counseling approaches and the differences between them.[60] Both patient education and psychosocial counseling are important, and genetic counselors may show variation in which approach they focus on.[54] Assessment of communication skills during training may help ensure that professional genetic counselors can master and balance both approaches with their patients.

2.0 MATERIALS AND METHODS

This is a qualitative study that used semi-structured phone interviews to conduct a needs assessment. Before any participants were contacted, the study design and resources were reviewed and approved by the University of Pittsburgh Institutional Review Board (IRB). The approval letter can be found in Appendix A.

2.1 INTERVIEW GUIDE

An interview guide was created to investigate how genetic counseling programs currently assess students' communication skills and to gauge interest in a new assessment tool. This guide consisted of seven main questions, with follow-up questions to encourage discussion. The full interview guide can be seen in Appendix B.

Program directors were first asked what the five most important communication skills that they personally want students to learn or develop during their training. This was not only asked to obtain relevant data regarding definitions of communication skills and what may be important in the field of genetic counseling, but to put participants in the mindset of what communication means to them. They were then asked how the program assesses the skills they listed and whether or not they think other programs do the same thing.

The interview guide then asked if the assessment in the participant's program is effective, and then to discuss the barriers to effective assessment. Lastly, participants were asked if they would be interested in using a new assessment tool, and what they would like to see in this tool. These questions elicited possible barriers programs may encounter assessing communication and addressing deficiencies seen in students, which should then be taken into account when creating a new tool.

2.2 RECRUITMENT

Directors of genetic counseling programs in the United States and Canada are eligible for membership in the Association of Genetic Counseling Program Directors (AGCPD). AGCPD members can participate in an association email listserv. A recruitment letter was sent through the genetic counseling program director listserv. An original email and a reminder email were sent through this listserv for recruitment of research participants. The purpose of this letter was to introduce the study to potential participants, program directors, and to request that they respond if interested in participating. A copy of this letter can be found in Appendix C. At the time these emails were sent out, there were 35 genetic counseling programs that were accredited by the Accreditation Council for Genetic Counseling (ACGC).

2.3 DATA COLLECTION

Typically each phone call lasted around 20 minutes and included a mixture of open and closed-ended questions. At the beginning of the phone call, before the interview was conducted, an informed consent script was reviewed. Participants were given an overview of the study and its purpose. It was then reviewed with them that there are no foreseeable risks associated with this project, there are no direct benefits, participation is voluntary, all responses are confidential, and no identifying information will be released in any publications. After they were given the opportunity to ask questions, and confirmed that they were willing to participate, the interview began. The full consent script can be found in Appendix D.

Of 35 programs, 16 program directors (45.7%) responded to the recruitment email expressing a willingness to participate in the survey. Reply emails were responded to with options for dates and times in which phone interviews could be conducted. After this process, 14 directors (40.0%) responded again and both scheduled and completed a phone interview. All 14 directors gave informed consent, and no directors withdrew from the study.

Phone interviews were transcribed by the interviewer during each interview, as they were not audio-recorded. The notes taken were then used for data analysis.

2.4 DATA ANALYSIS

Thematic analysis is a research approach created to interpret qualitative studies by finding themes that describe and categorize the data. Though there are recognized methods, the interpretation of data and the actual process of the analysis is often more flexible than

quantitative studies.[61] This study combined multiple methods of analysis in order to ensure that all of the data could be described and interpreted in a detailed manner, but a general use of Braun and Clarke's phases of analysis were used: "1. Familiarizing yourself with the data; 2. Generating initial codes; 3. Searching for themes; 4. Reviewing themes; 5. Defining and naming themes; 6. Producing the report."[61]

Notes from the phone interviews were read multiple times, with codes and themes written and taken note of. Braun and Clarke's "phases of thematic analysis" were used in coding.[61] Due to the nature of the interviews, some questions generated bounded, or closed-ended information, while other questions generated discussion and more robust data. Therefore, different coding approaches were taken depending on the question and its generated data. The questions, seen in the full interview guide in Appendix B, are laid out below with their coding processes.

Question 1 asked program directors what the five most important communication skills that they would like students to learn or develop are. This question therefore generated a list of communication skills. To analyze this list, Braun and Clarke's deductive coding approach was used, drawing from the practice-based competencies. Items from the list were coded and compared to the communication skills mentioned in the competencies. This approach has also been described by Hsieh et al. as directed content analysis, which uses existing theory and prior research as a foundation for the codes found in the data[62]

Question 2 asked how programs currently assess student's communication skills. This also generated lists that included different types of assessment. Because these types were similar across programs, and the information was bounded by known methods of assessment, thematic analysis was not necessary for this question. A frequency count was used to discover how many directors mentioned each type of communication assessment.

Questions 3, 4, and 6 are yes/no closed-ended questions, so a frequency count was again done for analysis. The follow-up to question 6, which asked program directors to discuss what they would like to see in a communication assessment tool generated their ideas for evaluation. Since these ideas were once again bound by types of assessment models, a frequency count of each idea was completed.

Question 5 asked program directors to discuss what they think some barriers are to effective assessment. This generated robust data that were coded using Braun and Clarke's thematic analysis, in which codes and themes were created using the directors' responses.

3.0 RESULTS

3.1 MOST IMPORTANT COMMUNICATION SKILLS

Program directors listed the five most important communication skills that they feel students should learn or develop during their training. The skills they mentioned, the themes used in coding for thematic analysis, and their connection to the genetic counseling practice-based competencies can be seen below in Table 1.

Table 1: Most Important Communication Skills

Theme	Skills Described by Participants	Associated Practice-Based Competency[58]
Cultural Competency and Adaptability	• Manage a session in a culturally responsive manner • Understand how the difference in the counselor and the patient might affect their communication (pitch, tone, direct vs. indirect, hierarchical, egalitarian) • Adjust your communication style to the patient's (they will not change it for you) • Cultural sensitivity/cultural competence: being able to start where your patient is, what is their medical cultural context, what is the path they have traveled down to get your office • Empathy: ability to understand the person you're talking to from a psychosocial and cultural standpoint* • Explain information and options to patients in a clear, culturally sensitive manner • Align with your client and have strategies to foster client alignment • Communicate what is relevant and meaningful for a family • Communicate complex information that is tailored to the person you are talking to* • Communicate with children and teenagers	"Apply genetic counseling skills in a culturally responsive and respectful manner to all clients"[58]

Table 1 Continued		
Eliciting from the Patient	• Assess patient understanding and clarify if needed • Elicit the patient's most important concerns or the patients priorities	"Establish a mutually agreed upon genetic counseling agenda with the client"[58]
Emotional Support	• Allow where the patient is emotionally or psychosocially to guide content • Show the ability to read patients and interpret their emotional state and understanding • Provide support • Use a number of counseling techniques and elicit patients emotions • Attend physically • Attend psychologically • Use verbal and nonverbal attending • Use psychological attending	"Employ active listening and interviewing skills to identify, assess, and empathically respond to stated and emerging concerns"[58]
Empathy	• Convey empathy, in a verbal or nonverbal way • Empathy: being able to put yourself in the client's shoes, and being able to receive empathy* • Advanced psychosocial skills: empathy • Primary and advanced empathy • Apply empathy • Empathy: ability to understand the person you're talking to from a psychosocial and cultural standpoint* • Show empathy and understand the role of the empathetic connection • Show empathy • Show basic empathy • Show advanced empathy	
Rapport Building	• Establish a comfortable working alliance through building good rapport • Build rapport with contracting & agenda setting skills	
Listening	• Have an appreciation for the power of listening • Show active listening skills • Show critical listening skills • Show listening skills • Show effective listening	
Nonverbal Skills	• Show both receptive and expressive nonverbal skills • Express good nonverbal communication (appropriate eye contact and body language) • Use verbal and nonverbal cues/communication skills • Understand the idea that so much is conveyed by nonverbal cues • Show the ability to interpret both verbal and nonverbal patient responses (listening and observing)	

Table 1 Continued		
Conveying Information Clearly	• Precisely and accurately explain a genetic mechanism or etiology or phenomenon • Convey complex knowledge • Communicate precisely and effectively in written and oral forms • Use plain language • Provide relevant information that is understandable and meaningful to the patient • Use clarity and thoughtfulness • Communicate complex information that is tailored to the person you are talking to* • Be flexible: modify individual plan based on the patient sitting across from them • Have flexibility • Show adequate written communication skills	"Demonstrate the skills necessary to successfully manage a genetic counseling case"[58] "Effectively educate clients about a wide range of genetics and genomics information based on their needs, their characteristics and the circumstances of the encounter"[58]
Asking Questions	• Guided questioning/interviewing • Use open-ended questions • Structure your sessions with clients so it is a two-way conversation and not a monologue • Ask clear and concise questions • Ask broad questions (basic interviewing skills)	"Use a range of genetic counseling skills and models to facilitate informed decision-making and adaptation to genetic risks or conditions"[58]
Other	• Use validation and normalization • Use reflective communication strategies	
	• Effectively communicate in situations where you cannot assess nonverbal cues (phone counseling)	"Understand how to adapt genetic counseling skills for varied service delivery models"[58]
	• Facilitate a decision	"Promote client-centered, informed, non-coercive and value-based decision-making"[58]
	• Have honesty and integrity: communicate what you can and cannot do, what you know and what you do not know • Be self-aware and recognize what your barriers are	"Demonstrate a self-reflective, evidenced-based and current approach to genetic counseling practice"[58]
	• Control the session • Be able to give bad news • Handle angry or difficult patients • Keep things on track in an appropriate time frame using time management skills • Respond in an immediate way to issues that arise in session	No directly-related practice-based competency

*this skill fits into more than one theme and/or competency, so it is listed more than once

3.2 HOW PROGRAMS ASSESS COMMUNICATION SKILLS

The topic of "communication skills" is broad and participants often answered questions differently based on their own perceptions. They described communication that ranged from psychosocial to written to presentation skills to communication with patients, supervisors, and the interdisciplinary team. The ways that programs assess these skills mostly rely on the ACGC practice-based competencies, but also rely on the definition of communication skills that is most important to the program and its director(s).

All 14 participants mentioned that a clinical evaluation form is completed by supervisors at rotations, usually at the end of the rotation but sometimes at the midpoint as well. Out of the 14, 10 participants also mentioned that these forms are influenced by the practice-based competencies: often the competencies are listed out and then scored by some type of Likert or 3-point scale. This was by far the most common type of assessment mentioned by program directors. One director mentioned that everything that is taught in genetic counseling programs involves some form of communication.

Standardized patients or simulations were mentioned by eight participants. Of these, five also mentioned that some of these interactions are video-taped for further evaluation, which often includes self-reflection by students. Role plays, often posed as a less formal simulated patient, were mentioned by 11 participants.

Informal feedback, given verbally from supervisors, directors, and sometimes fellow classmates, was mentioned by 11 of the 14 participants. Due to the nature of the supervisor-student relationship and clinical rotations, this is likely the most common type of feedback. Directors mentioned that although formal evaluations are only done once or twice per rotation, supervisors often have some sort of discussion with their students after each patient. Only three

participants mentioned that there is a specific form filled out after each patient seen, versus just informal discussions after the patient encounter is complete.

Communication skills taught in the classroom setting were mentioned by five directors of programs. Classes discussed included professional issues and presentation giving, advanced techniques (e.g., decision-making, confrontation working with couples, risk communication, difficult clients), psychosocial courses and medical communication. Another program considers these skills in one part of their comprehensive examination. Students write down their approach to clinical scenarios.

Some forms of assessment were mentioned fewer than three times. These include assessment of written communication and journaling as a form of critically thinking. Others discussed that inter-rater reliability is considered during assessment of standardized patient experiences, and therefore assessment is done by more than one supervisor or professor. Self-evaluation was also discussed by some directors. A couple of others mentioned the use of mental health or psychology professionals in teaching and assessing psychosocial skills.

When asked if other programs assess skills in the same way, or what might be different or unique about the program, not a single participant was sure of the assessment or structure of other programs. Some mentioned that they have used tools from other programs, but none could definitively explain how other programs function regarding this matter. It was recognized that simulations are often done by others and that the competencies are often used on evaluation forms. Uncertainty was expressed in phrases like “I don’t know” and “I would assume.” One director did mention that all programs have something similar, since all must hold themselves accountable to the ACGC.

3.3 IDEAS FOR A NEW ASSESSMENT TOOL

Most program directors mentioned that they would be interested in trying a new assessment tool, and many were enthusiastic about both using and sharing new materials. When asked what they would like to see in a new tool, every idea mentioned was a technique that is already being used in at least one of the other programs interviewed.

Of the 14 program directors, three said that they did not have any ideas for what a new assessment tool should look like, stating that either they believe that assessment is successful as is, or that a tool may not increase the quality of a supervisor's skills. A fourth director noted that we must first identify a problem with the way we assess communication before creating this tool.

The other 11 program directors noted that they would be interested in at least trying a new tool. Four of these 11 felt that this tool should be quick and/or easy to use, so it would not be an extra burden on supervisors or students. One program director felt that the tool should come with a guide explaining how the tool should be used and how it would help programs meet accreditation standards. Another director noted that the skills being assessed should be defined on the tool.

Four of the 11 aforementioned expressed interest in a tool that would take into account where the particular student is in his or her training. The grading on a continuum would allow students to be assessed differently based on the experience they have had in their classes and rotations. Two of the program directors mentioned that the tool should have some sort of validity or theoretical foundation in the literature.

One director mentioned reducing inter-rater reliability, while another focused on a need for more feedback in the classroom from both instructors and peers. Other issues that were mentioned included giving students a chance to be assessed on the more difficult patient

encounters, which supervisors may often take over during a session, assessing differently based on the difficulty of a patient encounter, and delving into the details of communication skills instead of just broad definitions.

Three directors felt that self-reflection should be involved in an assessment tool, and two mentioned that evaluation directly from the patient or client would give a student a better understanding of his or her success in a genetic counseling session.

3.4 BARRIERS TO EFFECTIVE ASSESSMENT

Reponses from the question “what do you think are some barriers to effective assessment?” were coded into three main themes: supervisor-driven, student-driven, and other barriers.

3.4.1 Supervisor-Driven Barriers

The supervisor-driven barriers were those in which the actions of the genetic counseling supervisor (the individual listening to the student’s counseling and rating/commenting on her skill level) were the cause of ineffective assessment. Barriers that fell into this theme included that supervisors have individual or personal preferences and styles of counseling. Their comments may be specific to that style, instead of general ways to ensure effective communication. Therefore, other directors mentioned that feedback is not always consistent across supervisors. This was mentioned by some as a need for better inter-rater reliability.

3.4.2 Student-Driven Barriers

The student-driven barriers were those in which the actions or reactions of the genetic counseling student were the cause of the ineffective assessment. Program directors mentioned that anxiety during a counseling session may affect how a student performs or communicates. Evaluation of skills depends on how open the student is to hearing feedback, or if a student becomes emotional when being given negative feedback. One director mentioned that tension between classmates can affect a student's performance. Others mentioned that the student's baseline abilities can be thought of as a barrier. Some students enter the program with exemplary communication skills, while others have more room for growth. Directors said that this can make evaluation difficult for supervisors.

3.4.3 Other Barriers

The most commonly mentioned barrier was that evaluation of communication skills is subjective. This barrier may not have a solution, but the acceptance of the subjectivity may be helpful moving forward towards more tools and focus on assessment of communication. A few directors defined assessment as an "art." It may be difficult, but even art is taught, practiced, and evaluated in many settings.

4.0 DISCUSSION

The goal of this research was to perform a needs assessment to explore how genetic counseling training programs currently evaluate students' communication skills and their opinions on a new evaluation tool.

4.1 MOST IMPORTANT COMMUNICATION SKILLS

Question 1 of the interview asked program directors to list what they think are the most important communication skills a student should learn or develop during their training. When responses were analyzed using a deductive thematic analysis approach, most of the skills mentioned by program directors correlated with at least one of the genetic counseling practice-based competencies. This can be seen in Table 1. Yet, the competencies could not fully encapsulate the essence of the skills identified by program directors as most important. For example, empathy was mentioned ten times as one of the most important skills for students to develop, but it is listed in the competencies only once as a way to build a relationship. This same competency covers building rapport, which was mentioned twice, and listening, which was mentioned five times. Each of these skills is listed in the genetic counseling literature as an important component of genetic counseling sessions.[1,55,63,64] In one genetic counselor's experience, Spencer (2015) notes that "Although my graduate training gave me a solid

foundation on which to develop increasing amounts of empathy, ultimately it was my patients and their generosity in sharing personal experiences and stories that taught me the most about empathy."[64] This account further emphasizes the need for supervisors to comment on empathy during students' time in the clinic, where they may have the best opportunity to learn this skill. If program directors find skills like empathy to be important, and this importance is embedded in relevant literature, perhaps the competencies should emphasize them more clearly. The competencies cover all skills that genetic counselors should master, not only communication skills, so the inclusion of multiple skills into one competency may be warranted, but it may also distract genetic counselors from focusing on each skill individually.

Five communication skills were mentioned by program directors as important that did not have explicit connections to the competencies. Although they were each mentioned only once, this may also be an indication that communication skills could be listed in more detail in the competencies. The skills to control the session, manage time effectively, and respond in an immediate way to issues that arise may all allude to session management and control. A competency emphasizing the completion of all goals of the session within an appropriate time frame may be an addition that would incorporate the skills that these three program directors considered important enough to mention.

Although the skills listed were separated by theme and by the related competency, many of these skills are connected. A genetic counselor may need to use listening skills while building rapport, or use nonverbal skills to display empathy. When creating an assessment tool, this complexity may create a challenge. The skills evaluated in a tool should therefore be specific and defined.

The list of skills was created by directors of training programs, whose careers indicate that they are qualified individuals to make judgments on what skills should be incorporated into curricula and what successful genetic counselors should be able to accomplish. Therefore, the list should be taken into account when considering how to ensure that students leave their training programs having mastered them. If a new assessment tool were to be created, these skills should be explicitly incorporated, so deficiencies can be discovered and corrected.

It is important to emphasize that participants were asked to list the five most important communication skills on the spot. They did not have the practice-based competencies in front of them to reference, nor did they have extensive time to consider the needs and values of the entire curriculum. The practice-based competencies were originally written by a team of experts who rigorously discussed exactly what skills are necessary for the profession. They were decided upon by process that was both collective and narrative that spanned 11 months.[57] Genetic counseling program directors, expert consultants, ABGC board members were involved in the identification of the competencies.[57] They were meant to be used for accreditation standards and program development, and they were written as a list that was meant to evolve with the profession.[57] The competencies have been revised to reflect the evolving nature of the field. There are currently 22 competencies divided into four domains.[58] Provided for each competency are examples of skills and activities that may assist students in meeting the competencies.[58] The competencies that have to do with communication skills should also be included in an assessment tool.

4.2 HOW PROGRAMS ASSESS COMMUNICATION SKILLS

All programs assess communication skills in some way, but no program is exactly the same. Although every program director indicated that her program assesses communication skills, and described how assessment takes place, it seems that communication training and communication assessment were conflated. Standardized patients, role plays, and written assignments are all forms of training. They do not encompass how the student was evaluated on that training. Some forms of direct assessment were mentioned, like evaluation forms based on the practice-based competencies and informal discussions after patient interactions. Program directors mentioned these forms of assessment among forms of training, without specifically distinguishing the two. If directors decide to reevaluate their current forms of assessment to consider a new tool, the distinction between training and assessment should be discussed. Programs may be training their students well, but they might not be focusing on the formal assessment of students to ensure that the training was successful.

Genetic counselors are known for their excellent communication skills[52]. Some program directors noted that employers of their former students have never mentioned a concern on surveys designed to assess alumni competency. This suggests that their students achieved competency in communication skills. Still, this does not provide a systematic way to evaluate the communication skills of genetic counseling students during their training. As the need for genetic counselors increases and more training programs are created, a standardized and effective tool to assess student communication skills may be helpful to keep standards for new genetic counselors high, ensure all training programs are successful at both teaching and assessing communication skills, and allow new programs to start out with effective method of assessment.

Only some of the methods that program directors mentioned for evaluating communication skills have an explicit foundation in the literature. As discussed in Chapter 1 of this document, standardized or simulated patients are a well-studied and accepted form of assessment in medicine.[6,36–39] They are also used by many genetic counseling programs and have been shown to be a valid teaching tool for genetic counselors.[59]

None of the other forms of assessment have a strong foundation in the literature. The practice-based competencies themselves are valid through the rigorous approach used to create them and their widespread acceptance in the genetic counseling field. When the competencies were originally created, it was recognized that "the use of the competencies for student performance assessments and practitioner evaluations will foster the collection of outcome measures for effective teaching, clinical supervision, and genetic counseling practice."[57] This may be the reason that the majority of program directors mentioned evaluation forms based on the competencies. There has been no study to our knowledge that has explored the effectiveness of using the competencies on an evaluation form. As previously discussed, the competencies do not place the same emphasis on certain communication skills that program directors did when listing the most important ones.

If the gold standard evaluates all aspects of communication on a day-to-day basis, then a form that is used at the midpoint and end of each clinical rotation is not fulfilling that need.[4] Most of the programs that mentioned evaluation after every patient seen explained that it is an information process that depends on the supervisor's time to discuss the student's strengths and weaknesses. Research shows that medical students can feel unsupported when they do not have the opportunity to discuss and debrief a patient interaction with their supervisors.[31] Informal evaluation can be therefore helpful, but it is also sporadic and leaves no documentation of the

student's improvements, deficiencies, or successes. A quick and simple tool that would provide a formal case-by-case assessment and document this for students, supervisors, and program directors should be considered.

4.3 IDEAS FOR A NEW ASSESSMENT TOOL

The ideas generated by program directors regarding what a new assessment tool should look like must be taken seriously when creating such a tool. Many of them address concerns that have been discussed in the literature as well, like inter-rater reliability, changing assessment depending on where the student is in her training, and evaluation from all individuals involved in the session (self-assessment, supervisor assessment, and patient/client assessment).[4,24,37]

Although the literature discusses the concerns brought up by program directors, there is no comprehensive assessment tool that incorporates all of the directors' ideals. There may not be a single tool that can do everything that they listed, but considering all of the ideas when creating a tool could allow for creativity and expansion of currently used and accepted tools.

4.4 BARRIERS TO EFFECTIVE ASSESSMENT

Most of the barriers to effective assessment listed by genetic counseling program directors are those discussed by others in the literature and possibly difficult to overcome. These barriers include the subjectivity of evaluating communication, student-driven barriers like anxiety and becoming emotional when given negative feedback, and supervisor-driven barriers like basing

feedback on individual style preferences and lack of inter-rater reliability. Students who are anxious about a supervisor's response to mistakes may not be able to focus on the session properly.[55] Students who magnify mistakes may influence supervisors to be more careful in giving corrective feedback or voicing deficiencies to the student.[55] Inter-rater reliability is a concern when evaluating students in the medical field as well, and no clear solution has been suggested in the literature.[37] Genetic counseling styles have also been noted to vary, so a supervisor may have a personal bias depending on her own training and her unique communication style.[54]

Though the barriers mentioned by program directors have been acknowledged by other research, solutions have rarely been discussed. One of the best ways to avoid these barriers may be training on how to give and how to receive feedback.[55] *A Guide to Genetic Counseling* notes that "just as supervisors have a responsibility to provide feedback appropriately, students have a responsibility to appropriately receive it."[55] The textbook then provides a guide on how to supervise and how to receive feedback, including personal reflection, and accepting both positive and corrective feedback.[55]

A new assessment tool will not make evaluating complex communication skills less subjective, but it may help supervisors consider this barrier and work towards unbiased objectivity. A new tool will not prevent all students from being vulnerable or resistant to feedback, but if it is standard for every patient, it may prepare students for what to expect and how to consider improvement in the components evaluated. These barriers should not be forgotten even if they cannot be overcome, so problems can be addressed and tools created can reduce the barriers as much as possible.

4.5 STUDY LIMITATIONS

Small sample size and lack of blinding could possibly contribute to bias in these results. Blinding was not possible in this research, because director's contact information was given in order to call them to complete the interview. Only 40% of program directors completed the interview, meaning that the majority of directors could have different opinions and ideas than those interviewed. If every director responded, the results may have been different. Participation in this study was voluntary, so the results could be a reflection of selection bias. Those who agreed to participate may have a particular perspective that is not necessarily representative of the rest of the program directors.

This study involved only genetic counseling program directors, who may not be directly supervising students in the clinic or practicing clinical counseling. Their opinions may therefore be focused more on curriculum, with less of an understanding of the assessment that occurs day-to-day between supervisors and students.

Program directors have very busy schedules, so interviews were arranged to accommodate busy professional lives and conducted concisely. Interviews over the phone also only gave directors the opportunity to answer questions on the spot. A written survey may have given the opportunity to consider their responses more carefully. These phone interviews were also not audio-recorded and therefore not transcribed. A word-for-word transcription may have been helpful to reference during analysis of the results.

A more experienced interviewer may have been able to pick up more nuanced data by asking specific follow-up questions. For example, it appeared that program directors were possibly conflating training with assessment, and follow-up questions could have been asked to

address this issue in a more thorough manner. Though some of this discussion was present during interviews, more consistent attention to this detail may have led to more robust data.

The limitations of this study should be considered when using the data to create new communication tools or when performing future research regarding the assessment of genetic counseling students' communication skills.

4.6 FUTURE RESEARCH RECOMMENDATIONS

Before an effective communication tool is created and assessed, more research on this subject may be useful. Future studies should focus on interviewing other stakeholders involved in communication skill assessment. Students and supervising genetic counselors are the individuals affected most by assessment tools, so their opinions would be important to understand regarding their views on current evaluation in the clinic and on what could improve in a new tool.

A meeting of program directors at the National Society of Genetic Counselors (NSGC) Annual Education Conference (AEC) may be helpful to discuss future plans, concerns, and opinions together. Since program directors were mostly unaware of how other training programs assess communication skills, and since this topic is important in the growth of the genetic counseling field, a discussion amongst all directors may open up the lines of communication for future collaboration. As a meeting resembling a large focus group, this discussion could be audio-recorded and results could be analyzed to supplement the results of our research study.

Creation of a new assessment tool may be done best if focus groups of stakeholders are highly involved in every step of its creation. Experts in the field, supervisors, and students could give the best insight into what a tool should look like, and which aspects that they found ideal in

a tool are realistic to incorporate. Once the tool is created, it should be assessed for effectiveness. A discussion of one way to create this tool and ways to test its effectiveness is discussed in the next section, Public Health Chapter.

5.0 PUBLIC HEALTH CHAPTER

The research done in this needs assessment has concluded that genetic counseling programs may benefit from a new communication skills evaluation tool that is based within an appropriate theoretical framework and relevant literature, which is currently lacking from genetic counseling programs. In this chapter, we describe an intervention fidelity monitoring tool that could be the foundation for such a tool and discuss what could be done to implement this tool in training programs.

5.1 INTERVENTION FIDELITY MONITORING

Bellg et al. describes treatment fidelity as "the methodological strategies used to monitor and enhance the reliability and validity of behavioral interventions."[65] This is also known as intervention fidelity monitoring (IFM).

Research may commonly be thought of as detailed and particular, in a lab with a petri dish. This type of wet lab research, when recorded meticulously and done precisely, can be easy to replicate. It may contain specific amounts of chemicals and time to complete certain tasks. Consistent outcomes from behavioral research can be more difficult to attain because similarly situated people may not respond the same when asked the same questions or when told the same

things. In order to help ensure that behavioral interventions can be replicated with the same results, to a reasonable degree, fidelity monitoring is used.

5.1.1 Four Supports

The IFM strategy described here is one developed and used in Dr. Doug White's *Family Support Intervention in Intensive Care Units*, or "Four Supports" research study.[2] This is an intervention to improve surrogate decision-making for critically ill adults. Interventionists act as palliative/critical care team members and are solely focused on the psychosocial support of caregivers who have loved ones at the hospital in intensive care. "Four Supports" refers to the four types of support that the interventionist is meant to provide the surrogate in coordination with the clinical team: emotional support, communication support, non-directive decision support, and anticipatory grief support.[2] Interventionist interactions with surrogates are audio-recorded, and these audio recordings are audited by trained researchers to assess how well complex communication skills were used and how well the interventionists adhered to the research protocol.[2]

The entire intervention fidelity monitoring process includes training of interventionists, a monitoring plan that includes self-assessment by interventionists through a checklist and assessment of support and communication through audio-recorded sessions, weekly supervision sessions, quarterly booster sessions, and response to deficiencies identified in these processes through remediation. The monitoring plan, will be described, as it is most relevant to the evaluation of genetic counseling communication skills.

The monitoring process is detailed, focusing on each individual session that the interventionist is expected to complete with the ICU team and the family involved in the case. These sessions are listed below:

5.1.1.1 Sessions with the Family

First interaction with the family – the first meeting includes the interventionist explaining her role and learning about the family and the patient.

Pre-conference with the family – this meeting occurs before the clinician-family conference and includes anticipatory guidance regarding what the conference will entail, eliciting family understanding and values, and completing a question prompt list of questions that families may have regarding their loved one's care and prognosis.

Clinician-Family conference – these conferences are standard of care for critical care teams. The interventionist is present for support and may help the family ask questions and understand medical discussions.

Post-conference with the family – this meeting allows the family to debrief after the conference with the physician. Misunderstandings can be addressed, and concerns and questions may be elicited.

Daily check-in with the family – interventionists have daily contact with families enrolled in the intervention to respond to their needs and maintain the relationship.

Life closure session with the family – if a family chooses to focus the patient's needs on comfort, this session will allow the family to receive spiritual care as needed, to have a life review facilitated to tell stories about their loved one, to discuss what might occur during the dying process, and to give the family time and emotional space to say goodbye.

5.1.1.2 Sessions with the ICU Team

First conversation with the ICU team – the first meeting includes the interventionist explaining her role to the attending physician, or proxy, and emphasizing that the interventionist can benefit the critical care team.

Pre-conference with the ICU team– the interventionist will elicit the physician's goals for the clinician-family conference and share information about the family's questions and prognostic understanding.

Post-conference with the ICU team – the interventionist will reflect on the meeting with the physician, ensure a shared understanding of next steps, and offer help in any way.

Daily check-in with the ICU team – interventionists have daily contact with physicians enrolled in the intervention to respond to the ICU team's needs and maintain the relationship.

5.1.1.3 Sessions with Control Subjects

The control group of the intervention includes two education sessions in which support is avoided and the interventionist only describes details about the ICU. We will not focus on the control group, as genetic counseling skills and values are embedded in the types of support that are the core of this behavioral intervention. Avoiding such support would be in direct opposition to the goals that the field of genetic counseling has created.

5.1.1.4 Assessment of Sessions

One assessment done in IFM is overall adherence to the protocol. The overall percent compliance with conducted daily sessions is interventionist self-reported data in which for every case, the interventionist records whether or not each session occurred on the schedule according to the protocol. If a deviation from the protocol occurred, the interventionist will also record a

reason for each deviation. Overall adherence considers the performance of the interventionist in scheduling sessions, not including variation related to family or clinician participants. Session-specific compliance rates consider deviations related to clinician and family participants.

Assessment in IFM also includes the analysis of audio-recorded sessions by independent raters. This data are derived from a random sample of 20% of audio-recorded sessions evaluated for quality using fidelity monitoring criteria. For each session evaluated, a session-specific form is completed by the evaluator. An example of one of these forms can be found in Appendix E. Each form contains key components that are evaluated based on the session's purpose, like "provides emotional support." A list of the key components evaluated for each session can be found in Appendix F. Raters of audio-recorded sessions go through a rigorous training. After 20% of all sessions are evaluated, a second rater listens to and evaluates a portion of these (one session per month), and inter-rater reliability is calculated. Sessions that either receive poor quality scores or poor inter-rater reliability scores are addressed in supervision meetings, so problems can be discussed and resolved.

5.2 CREATING A NEW COMMUNICATION ASSESSMENT TOOL

The intervention fidelity monitoring (IFM) tool described above and shown in Appendix E has many of the features described by genetic counseling program directors as ideal for a new communication assessment tool. The needs assessment determined that directors would like to see a tool that is easy to use, does not take much time for supervisors to fill out, and is based in the literature. This tool also allows for formal evaluation after each genetic counseling session, which could add to the forms used based on the practice-based competencies that supervisors

usually only fill out at the midpoint and endpoint of each clinical rotation. Evaluation forms filled out more regularly may allow for a student to track her progress and improvement more easily and allow supervisors to track inter-rater reliability. The IFM tool described was created to evaluate communication and psychosocial skills, so its principles could easily be translated into the genetic counseling field.

In order to create a new standard tool, it would be important to first get the opinions of stakeholders. As discussed in the "Future Research Recommendations" section, this needs assessment is the first step towards understanding what tool would be the most effective. Discussions with students and supervisors may be helpful in revealing their needs in an assessment tool. The actual development of the tool should be done with strong recommendations from respected members of the genetic counseling community who have extensive experience and knowledge regarding communication skills in the field. Next, what this tool could look like is described, recognizing that relevant studies and recommendations have not yet been pursued.

5.2.1 Translating the Tool from Critical Care to Genetic Counseling

The objective is to create a tool based on the *Four Supports* intervention fidelity monitoring (IFM) model. As described above, this format is already set to change the key components being evaluated depending on the type of session. In genetic counseling, practice areas could be broken down into three main categories of pediatric, prenatal and cancer sessions or into more specific categories. During the needs assessment, some program directors mentioned the need to assess difficult sessions differently, or to be able to assess students based on where they are in the program. A breakdown like this may be possible, or sessions within the different practice areas

of genetic counseling. In any type of breakdown of skills, more than one evaluation form may be helpful to encompass the different goals of genetic counseling depending on the type of session. For example, pediatric evaluation forms could include different key components for types of patient indications (connective tissue disorder, developmental delay, multiple congenital anomalies, etc.) or types of session goals (initial consult, follow-up appointment, result disclosure), or types of testing that will be ordered and therefore must be explained (microarray, exome, connective tissue panel, single-site). Some of the examples may be too extensive or overwhelming, but these types of breakdowns are what should be considered by stakeholders when creating the tool.

The key components evaluated for each session should be considered carefully as well. Some of the components may be the same as those in the *Four Supports* IFM form. Many of the IFM key components listed in Appendix F are quite applicable to genetic counseling sessions, so the use of these forms as a basis for a new tool is warranted.

5.3 IMPLEMENTATION OF THE TOOL

5.3.1 Testing the Effectiveness of the Tool

As has been described in the literature, evaluation can be very difficult and complex.[4,6,35,55] The evaluation of this evaluation tool is therefore bound to be challenging. Much of this evaluation will likely depend on the opinion of students and their supervisors, who will be using it directly. While the tool is being tested, students should be asked intermittently if they feel that the assessment tool has helped them receive feedback, that the tool addresses communication skills,

and that the tool has helped them improve communication skills. Supervisors should be asked if they feel that the tool is easy to use, that the tool helps them assess a student's communication skills, and that the tool helps them recognize and express deficiencies in communication that a student should work on.

Though much of the tool's success depends on how students and supervisors feel about it, some quantitative evaluation of the tool can be done as well. When different supervisors use the exact same form for a student, and the sessions were not particularly difficult, inter-rater reliability can be calculated to test if the tool accurately evaluates a student's communication skills. As a student progresses throughout her graduate program, she should likely see improvement of scores on the evaluation forms. These scores should be tracked and can be graphed. In general, an improvement should be seen. This improvement would indicate that the tool is allowing for accurate assessment of communication skills.

5.3.2 How to Use the Tool in a Genetic Counseling Session

Here we provide an example of a cancer genetic counseling session and the educational and psychosocial issues that should be addressed during such a session. Providing such an example may allow us to consider what is relevant for an assessment tool. We review the issues that may be discussed in a hereditary breast and ovarian cancer (HBOC) case.

5.3.2.1 Personal and Medical History

A genetic counseling session often begins by taking the patient's family and medical history. The National Comprehensive Cancer Network (NCCN) creates specific guidelines to identify individuals who should be offered genetic counseling and genetic testing for hereditary

predisposition to cancer based personal and/or family history.[66] For example, genetic counseling and genetic testing should be offered to an individual if she has had breast cancer before the age of 50, she has had breast cancer at any age and has another family member who has been diagnosed with breast cancer before the age of 50 or with invasive ovarian cancer at any age, if there is a known genetic mutation in the family, or a number of other indications in the personal or family history.[66]

5.3.2.2 Patient Education

Patients who fit criteria are provided with education about the genetics of hereditary breast and ovarian cancer during genetic counseling. Presenting this information in a personalized and understandable manner is an important part of communication during this type of session.

About 5-10% of breast and ovarian cancer is hereditary, meaning that it is caused by a mutation in a single gene that is known to increase one's risk of these types of cancer.[67] Of the hereditary breast and ovarian cancers, the majority are caused by mutations in the *BRCA1* and *BRCA2* genes. Women with mutations in one of these genes face a 56-87% chance of developing breast cancer (as opposed to an 8-12% risk for the general population) and a 27-44% chance of developing ovarian cancer (as opposed to a <2% risk for the general population) in their lifetime.[67] The risk of a second breast cancer, male breast cancer, prostate cancer, pancreatic cancer, and melanoma are also increased above that of the general population.[67]

Genetic mutations that lead to cancer predisposition are inherited in an autosomal dominant fashion, meaning that each child of an individual with a mutation has a 50% chance of inheriting that mutation and therefore the predisposition to cancer.

Patients should also be educated on the treatment and management guidelines for individuals who do have a *BRCA1* or *BRCA2* mutation and therefore a predisposition to the

cancers listed above. These include decisions between increased surveillance, chemoprevention, and preventative surgery. Surveillance includes self and clinical breast exams done more often, along with mammograms and MRIs.[66] For ovarian cancer, screening is not very effective so ultrasounds and CA-125 blood tests may be offered by a doctor, but they are not strongly recommended because of their weak ability to detect early signs of cancer.[66] Chemoprevention includes the option of medications like *tamoxifen* to reduce the risk of breast cancer in high-risk women, and the use of oral contraceptives for at least six years can reduce the risk of ovarian cancer.[66] Preventative surgeries are prophylactic bilateral mastectomy and oophorectomy, which are the best ways to decrease one's cancer risk (by about 95%).[66]

A patient should be educated so she understands her potential risks and what she might do about these risks to manage them. This may help her make a decision about whether or not she wants to have genetic testing done, what type of information she would like back from that testing, and what treatment or management she might consider if she does have a predisposition to cancer.

5.3.2.3 Test Evaluation and Ordering

If a patient chooses to pursue testing after being educated on the potential sequelae, her testing options should be discussed. A patient who does not like uncertainty might only like the testing (sequencing and deletion/duplication analysis) of the *BRCA1* and *BRCA2* genes. A patient who is interested in all of the information available and does not mind uncertainty may choose panel testing, which includes a list of genes that are known to increase the risk of breast and ovarian cancer. Some of these genes were discovered more recently, and therefore do not have long established management and treatment guidelines as the BRCA genes. Other genes are moderate risk, meaning that they do not increase the chance of cancer as much as the BRCA genes, and

therefore screening options may not be as extensive. These factors should be considered before a testing decision is made.

Potential results include a positive result, meaning that a mutation was found that is known to increase the individual's risk for cancer and therefore screening and management guidelines are offered; a negative result, meaning that no mutation was found so risks should be based on the patient's family history; or a variant of uncertain significance (VUS). A VUS indicates that a change within the DNA was discovered, but whether or not it affects the gene is unknown. The patient should not change screening or management based on a VUS, and other family members should not be tested for that change until more is known about it and it is reclassified as either a positive or negative result.

5.3.2.4 Psychosocial Issues

The issues that could come up in a cancer genetic counseling session like the one described above and the emotions that may need to be address are expansive. A patient might feel guilt for possibly passing a cancer predisposition down to her children. She might feel uncertainty in whether or not she should pursue testing or what testing she should pursue, or worried about the results that may come back. She may have been recently diagnosed with breast cancer and still dealing with the fear of her future, or confusion regarding her diagnosis, or some form of denial. She might be upset with the genetic counselor for bringing up difficult issues and potentially life-changing diagnoses and surgeries. Understanding and being prepared for these emotions will help a genetic counselor address them effectively using the communication skills discussed in this document.

5.3.2.5 Assessment

At the end of the genetic counseling session, the supervisor and student may sit down to debrief and discuss what went well and what the student could improve on. All of the communication skills that program directors mentioned in our needs assessment and listed in Table 1 could be necessary within this session. Empathy, cultural competency, nonverbal communication, and more should be assessed to make sure that the student is mastering these skills. Though not every skill will be used explicitly in every session, the supervisor should watch out for all of them. Other skills that should be assessed are the ability to elicit medical and family history and to convey the education information in an appropriate manner.

If these skills were assessed using the intervention fidelity monitoring model described, students would be given an overview of their performance of each important skill after every patient they saw with both quantitative evaluation to be able to track progress and qualitative evaluation to explain and supplement the quantitative measurements. It would ensure that a discussion occurred after every case and give students a standard form to expect every time they are the primary counselors. Such a tool could improve upon training programs and create a foundation for future assessment.

5.4 PUBLIC HEALTH EFFECTS OF AN ASSESSMENT TOOL

The logic model below in Figure 1 lists the potential public health effects of implementing a new communication assessment tool in genetic counseling training programs that is based off of the intervention fidelity monitoring model described above.

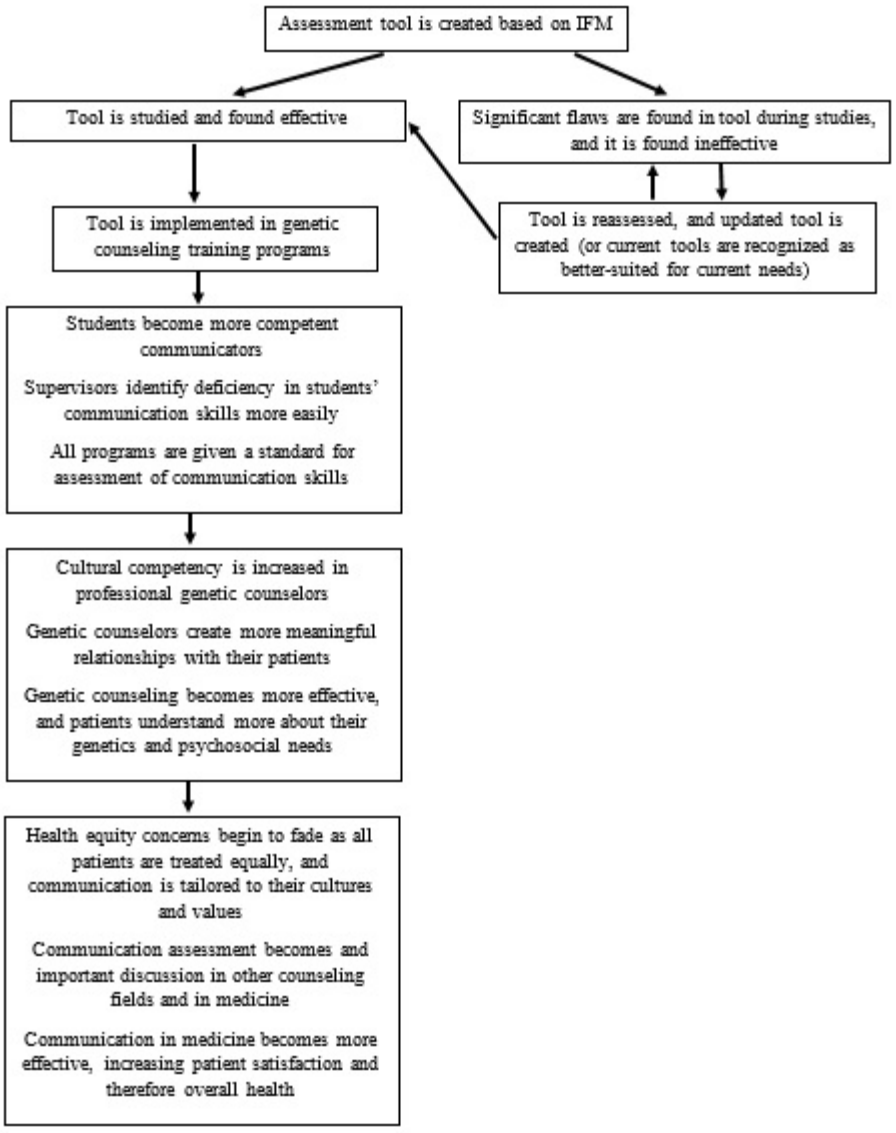

Figure 1: Logic Model for Program Implementing a New Communication Assessment Tool

This model is predicated on the literature that suggests when communication improves, patient satisfaction, health equity, and overall health improve as well in the long-term.[4,6,19] These outcomes prove that the investment in resources to create, study, and implement such a tool is worth it to work towards better communication skills in healthcare.

5.4.1 Ethical and Legal Considerations

Changing expectations for all genetic counseling programs and creating new standards for assessment requires logistical implementation of these standards into the ACGC's list of components that a program must have in order to be accredited. This could create a barrier for programs who cannot or do not want to use the assessment tool. If it is only a suggestion, and not a requirement, it may not have the same public health impact.

More strict requirements may also have an effect on the states that require a genetic counselor by law to be licensed in order to practice. Although this may seem like a barrier, high standards keep professionals successful and challenge them to continue improving the genetic counseling field.

Additional requirements may force programs to become more standardized instead of giving directors the autonomy to creatively come up with new assessment models. We recommend that the assessment tool be a supplement to what is already used in training programs. As previously discussed, no one tool will be able to obtain all of the goals of effective communication. One standardized tool may just assist programs in ensuring that communication is assessed with this tool at a minimum, and then use standardized patients, role plays, written assignments, informal discussions, and more to help students navigate the complexities of communication.

APPENDIX A: IRB APPROVAL LETTER

University of Pittsburgh
Institutional Review Board

3500 Fifth Avenue
Pittsburgh, PA 15213
(412) 383-1480
(412) 383-1508 (fax)
http://www.irb.pitt.edu

Memorandum

To: Rebecca Vanderwall

From: IRB Office

Date: 12/22/2015

IRB#: PRO15110607

Subject: Evaluation of Communication Skills in Genetic Counseling Training Programs: A Needs Assessment

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The above-referenced project has been reviewed by the Institutional Review Board. Based on the information provided, this project meets all the necessary criteria for an exemption, and is hereby designated as "exempt" under section

45 CFR 46.101(b)(2)

Please note the following information:

- Investigators should consult with the IRB whenever questions arise about whether planned changes to an exempt study might alter the exempt status. Use the "**Send Comments to IRB Staff**" link displayed on study workspace to request a review to ensure it continues to meet the exempt category.
- It is important to close your study when finished by using the "**Study Completed**" link displayed on the study workspace.
- Exempt studies will be archived after 3 years unless you choose to extend the study. If your study is archived, you can continue conducting research activities as the IRB has made the determination that your project met one of the required exempt categories. The only caveat is that no changes can be made to the application. If a change is needed, you will need to submit a NEW Exempt application.

Please be advised that your research study may be audited periodically by the University of Pittsburgh Research Conduct and Compliance Office.

APPENDIX B: INTERVIEW GUIDE (TELEPHONE)

Program:
Name of Director Interviewed:
Communication Log:
Interview Date:
Interview Start Time:
Interview End Time:

1. What are the 5 most important communication skills that you want students to learn/develop during their training (examples: nonverbal communication, cultural empathy/sensitivity, elicit patient understanding, balance of content and affect)?

2. Does your program assess these communication skills?

    How? Or if not, why?

3. Do you think that other programs do this?

    If not, what is different?

4. Do you feel that the assessment in your program is effective?

    Are all of the most important communication skills addressed?
    Are there quantitative or qualitative components, or both?
    Do the students receive consistent feedback?
    How often is feedback given?
    Do you feel that they can use the feedback to work on their communication skills?

5. What do you think are some barriers to effective assessment?

6. Would you be interested in using a new communication assessment tool?

    If so, what would you like on it that your current assessment does not have/do?
        Examples: Rating 1-3 for each skill
        More skills assessed
        Skills tailored to each type of genetic counseling session (prenatal, pediatric, cancer, etc.)

More consistency between assessments at different clinical training sites
Quantitative and qualitative assessment

7. Would you be willing to share with me some of your assessment tools with me via email?

APPENDIX C: RECRUITMENT LETTER (ELECTRONIC MAIL)

Dear Genetic Counseling Program Directors,

My name is Becca Vanderwall, and I am a genetic counseling student at the University of Pittsburgh. For my Master's thesis project, I am working with my faculty mentor Robin Grubs to conduct a research entitled titled “Evaluation of Communication Skills in Genetic Counseling Training Programs: A Needs Assessment.” The purpose of this research is to determine how complex communication skills are currently assessed in genetic counseling training programs. One of the goals of the project is to develop a comprehensive assessment tool for genetic counseling programs to use. Given your expertise in genetic counseling education and training, I am hoping you will consider participating in a phone interview. It should take approximately 15 minutes. If you are willing to participate, please reply to me at rav39@pitt.edu with your general availability to schedule a phone interview. Your participation would be greatly appreciated.

Thank you so much for your time,

Becca

--
Becca Vanderwall
Candidate for M.S. Genetic Counseling & M.P.H
University of Pittsburgh
rav39@pitt.edu

APPENDIX D: INFORMED CONSENT SCRIPT (TELEPHONE)

Hello, Dr. (insert name). This is Becca Vanderwall from the University of Pittsburgh. Thank you for your interest in my research project entitled "Evaluation of Communication Skills in Genetic Counseling Training Programs: A Needs Assessment." The purpose of this research is to determine how complex communication skills are currently assessed in genetic counseling training programs, and then to describe a novel Intervention Fidelity Monitoring strategy for a complex behavioral intervention that was developed and used for Dr. Doug White's "Four Supports" research study. Dr. Doug White is the Director of the Program on Ethics and Decision Making in Critical Illness and an associate professor at the University of Pittsburgh Medical School. He is also a co-mentor on my thesis project. His "Four Supports" study is an intervention to improve surrogate decision-making for critically ill adults. Interventionists act as palliative/critical care team members and are solely focused on the psychosocial support of caregivers who have loved ones at the hospital in intensive care.

This research is being conducted to gather the necessary knowledge to develop a complex communication assessment tool for genetic counseling. For that reason, we will be facilitating a needs assessment in the form of phone interviews with genetic counseling program directors. If you are willing to participate, I will need your contact information and will be eliciting details about how your program assesses students' communication skills. The interview will take approximately 15 minutes to complete. There are no foreseeable risks associated with this project, nor are there any direct benefits to you. You will not receive any compensation for your participation. Your participation is voluntary, and you may withdraw from this project at any time. All responses are confidential, and results will be kept on a secure, password protected computer. No identifying information will be released in any publications. If you have any questions after we have completed the interview, I can be reached at rav39@pitt.edu.

Do you have any questions at this time?

APPENDIX E: FOUR SUPPORTS IFM EVALUATION FORM EXAMPLE

Patient ID: _____ Date of Content Delivery: ____/____/____
Interventionist ID: ____ Rater ID___ Date of Monitoring: ____/____/____

First Conversation with the Family

Meeting Components	Yes	No	Quality Rating*	Comment
Objective Components				
1. Provide emotional support			1 2 3	
2. Establish a relationship			1 2 3	
3. Explain FSI Role (may be only reinforcement if family was just consented)			1 2 3	I
4. Understand Family Stressors and Structure			1 2 3	
5. Elicit family's understanding			1 2 3	
6. Orient the family to the ICU and review unit orientation materials			1 2 3	
7. Elicit family's questions and concerns			1 2 3	
8. Inquire about previously expressed healthcare preferences (AD)			1 2 3	
9. Finalize scheduling of first meeting (Plan for next steps)			1 2 3	
10. Give/Receive Contact Information			1 2 3	
Qualitative Components				
11. Incorporates • Asking permission • Anticipatory guidance • Bracketing • Summarizing • Pacing • Appropriate pauses • Maintaining central importance of patient as a person			1 2 3	
Overall Quality of the Intervention Session			1 2 3	
Delivery of content inconsistent with principles of the intervention/ outside the scope of the intervention* *(describe)				

* 1= poorly executed/to a minimal extent, 2=moderately well, but not completely/with deficits in quality, 3= with high quality/completely
**Offering pure opinion, unilateral decision-making, display of impatience, disrespect of pt/family values, fomenting or exacerbating conflict

Content Score: Total __/11=___% **Mean Quality Score____**
Overall Quality of the Intervention Session ___ **Delivery of Content Inconsistent with the Principles of the Intervention Y/N**

APPENDIX F: KEY COMPONENTS IN FOUR SUPPORTS IFM EVALUATION FORMS

Meetings with Family

First interaction with the family

Objective Components	Qualitative Components
• Provide emotional support • Establish a relationship • Explain FSI role (may be only reinforcement if family was just consented) • Understand family stressors and structure • Elicit family's understanding • Orient the family to the ICU and review unit orientation materials • Elicit family's questions and concerns • Inquire about previously expressed healthcare preferences (AD) • Finalize scheduling of first meeting (plan for next steps) • Give/receive contact information	• Asking permission • Anticipatory guidance • Bracketing • Summarizing • Pacing • Appropriate pauses • Maintaining central importance of patient as a person

Pre-conference meeting with the family

Objective Components	Qualitative Components
• Provide emotional support • Explain the purpose of the pre-conference and family meetings • Elicit family understanding/complete prognostic estimates • Explain principles of surrogate decision making • Conduct values elicitation exercise • Complete Question Prompt List (QPL)	• Asking permission • Anticipatory guidance • Bracketing • Summarizing • Pacing • Appropriate pauses • Maintaining central importance of patient as a person

Clinician-family conference

Objective Components	Qualitative Components
• Provide/ensure emotional support provided • Help family ask questions • Encourage participation • Listen for and address misunderstandings • Ensure discussion of treatment options, prognosis, patient values as appropriate • Ensure clear plan for next steps	• Summarizing • Maintaining central importance of patient as a person

Post-conference meeting with the family

Objective Components	Qualitative Components
• Provide emotional support and express empathy • Listen for key misunderstandings and concerns • Help family synthesize key information from the clinician • Respond to family needs; allowing them to guide content • Elicit concerns and questions	• Pacing and appropriate pauses • Convey active listening • Maintaining central importance of patient as a person

Daily check-in with family

Objective Components	Qualitative Components
• Provide emotional support • Elicit and attend to concerns/questions/practical needs • Ensure understanding of daily plan/plan for next steps	• Pacing and appropriate pauses • Convey active listening

Life closure session

Objective Components	Qualitative Components
• Provide emotional support and empathy • Elicit spiritual needs and involve spiritual care as needed • Facilitate life review • Create space for family members to say goodbye to patient • Offer to discuss what might occur during dying process • Elicit and attend to family's questions/concerns/practical needs • Offer an opportunity for family to gather at bedside	• Asking permission • Anticipatory guidance • Pacing and appropriate pauses • Convey active listening • Maintain central importance of patient as a person to care decisions

Meetings with Physicians

First interaction with physician

Objective Components
• Reintroduce study • Explain FSI role • Explain architecture • Emphasize benefit to ICU team • Elicit MD perception of family needs and patient status • Tentatively schedule first meeting

Pre-conference meeting with physician

Objective Components
• Elicit clinician's goals for meeting/perception of family's needs • Give tailored information to ICU team including clinician summary sheet • Remind the clinician of the role the FSI will play in the conference

Post-conference meeting with physician

Objective Components
• Continue rapport building • Reflect on impact of meeting and inquire how you can be of help • Provide update of what happened after meeting • Confirm shared understanding of plan of care/plan for next meeting • Elicit physician's perception of family's needs

Daily check-in with physician

Objective Components
• Check in with clinician about plan of care/patient coordination • Share information elicited from family • Inquire about tasks with which FSI can assist

Educational Control Sessions

Control Session I

Objective Components	Control Condition-Specific Requirements
• Introduces self and describes the purpose of the session. Explains limitations, specifically they are not part of the clinical team • Delivers content about key players in the ICU • Delivers content about important phone numbers • Delivers content about visiting hours and rules • Delivers content about the specific ICU in which the loved one is being treated • Delivers content about the rounding structures • Responds to family questions with informational content	• Avoids delivery of emotional support o Empathetic responses o Supportive gestures (touch, hug) • Avoids delivery of communication support o Coordination of communication with team o Information about family-clinician communication • Avoids delivery of decisional support o Discussion of prognosis o Discussion of values o Discussion of SDM role

Control Session II

Objective Components	Control Condition-Specific Requirements
• Introduces self and describes the purpose of the session • Delivers content about "Why does my loved one look like that?" (tubes, lines, bruising, edema) • Delivers content about "Why does my loved one act that way?" (sedation, analgesia, confusion) • Delivers content about "How does the ICU team monitor my loved one?" (monitoring devices, alarms) • Delivers content about "How does my loved one receive nutrition?" (NG/OG, TF, IVF) • Delivers content about "What is mechanical ventilation?" (ventilator, tracheostomy, ABG, weaning, suctioning) • Closure – reinforce this is the last session, wish them well, and remind them there will be a follow-up call	• Avoids delivery of emotional support o Empathetic responses o Supportive gestures (touch, hug) • Avoids delivery of communication support o Coordination of communication with team o Information about family-clinician communication • Avoids delivery of decisional support o Discussion of prognosis o Discussion of values • Discussion of SDM role

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