Extending the Reciprocal-Engagement Model of Genetic Counseling Practice:
An Observational Study of Counselor Behaviors During Simulated Genetic Counseling Sessions

Amelia Richardson[1], Patricia McCarthy Veach[2], Ian MacFarlane[3], Krista Redlinger-Grosse[3]

[1]Division of Maternal-Fetal Medicine, Department of Obstetrics and Gynecology, NorthShore University HealthSystem, Evanston, IL. [2]Professor Emerita, University of Minnesota.
[3]Department of Genetics, Cell Biology, and Development, Institute of Human Genetics, University of Minnesota, Minneapolis, MN.

Introduction

- A fully validated model of genetic counseling (GC) practice is needed to achieve NSGC's strategic initiatives in establishing empirically-based GC processes and outcomes that facilitate equitable and just patient care.
- **The Reciprocal-Engagement Model (REM)** outlines key tenets, goals, and preliminary strategies and behaviors used in GC clinical practice.[1]
- Since the REM's publication, studies have validated REM goals and extended REM strategies.[2,3,4,5,6,7]
- **Two notable gaps remain:** (1) a clear description of REM behaviors, and (2) a lack of observational studies using the REM as a framework.

What is the value of a model of genetic counseling practice?

STUDENTS: How do I prepare for clinical practice?

PATIENTS: What can I expect at my appointment?

PRACTITIONERS & RESEARCHERS: How do we improve our counseling services?

This study extends the REM by: (1) identifying GC behaviors through observation of simulated genetic counseling sessions, and (2) mapping those behaviors back to REM goals to begin to demonstrate how behaviors fit into the existing REM practice model.

Method

Sample

Transcripts of the **Master Genetic Counselor Video Series**[8] created as an educational tool in 2011

- Peer-nominated, expert GCs (*n*=8)
- Each GC recorded 1 simulated scenario (cancer, cardio, or prenatal) with medical actors
- Final dataset: 8 verbatim session transcripts (3 cancer, 3 cardio, 2 prenatal)

Master Genetic Counselor Series

Cancer: Pre-test. Patient's mom has a *BRCA1* mutation and recurrent breast cancer. She does not want genetic testing of *BRCA1*.

Cardio: Post-test. Patient is recently divorced, asymptomatic, with Long-QT 1 diagnosis after his symptomatic daughter received the same Dx.

Prenatal: Post-screen. Patient received a quad screen positive for T21, had a previous miscarriage, and has a sibling with T21. She is considering diagnostic amniocentesis.

Instruments

Helping Skills Verbal Response Scale (HSVRS) Behaviors[9]

Affect reflection: reflect client feeling	Advice: suggest alternative behaviors	Information: provide facts or resources
Content reflection: reflect client statements	Closed question: requires 1- or 2-word answer	Self-disclose: factual self-information
Influence: attempt to alter client views	Open question: requires an extended answer	Self-involving: personal reaction to clients

Reciprocal Engagement Model (REM) Goals[1]

Patient's family dynamics are understood by counselor and patient	Counselor and patient know patient concerns	Patient gains new perspectives	Patient is informed
Integrate familial and cultural context into counseling relationship and decisions	Counselor knows what information to impart	Facilitate collaborative decisions	Empowerment
Patient self-esteem is maintained/increased	Patient feels empowered and more in control	Counselor presents genetic information	Adaptation
Counselor characteristics positively influence process	Counselor and patient establish a bond	Establish working contract	Recognize patient strengths

Procedure

- Directed-content analysis of GC speech for each simulated session transcript
- HSVRS behaviors *(Fig. 1A)*: Expert coder (PMV) assigned behaviors to GC thought units
- REM goals *(Fig. 1B)*: Primary coder (AR) and expert auditor (KRG) identified REM goals, achieving agreement through iterative auditing
- Mapping *(Fig. 1C)*: Behaviors were mapped onto goals using matrix coding queries in NVivo software (AR)
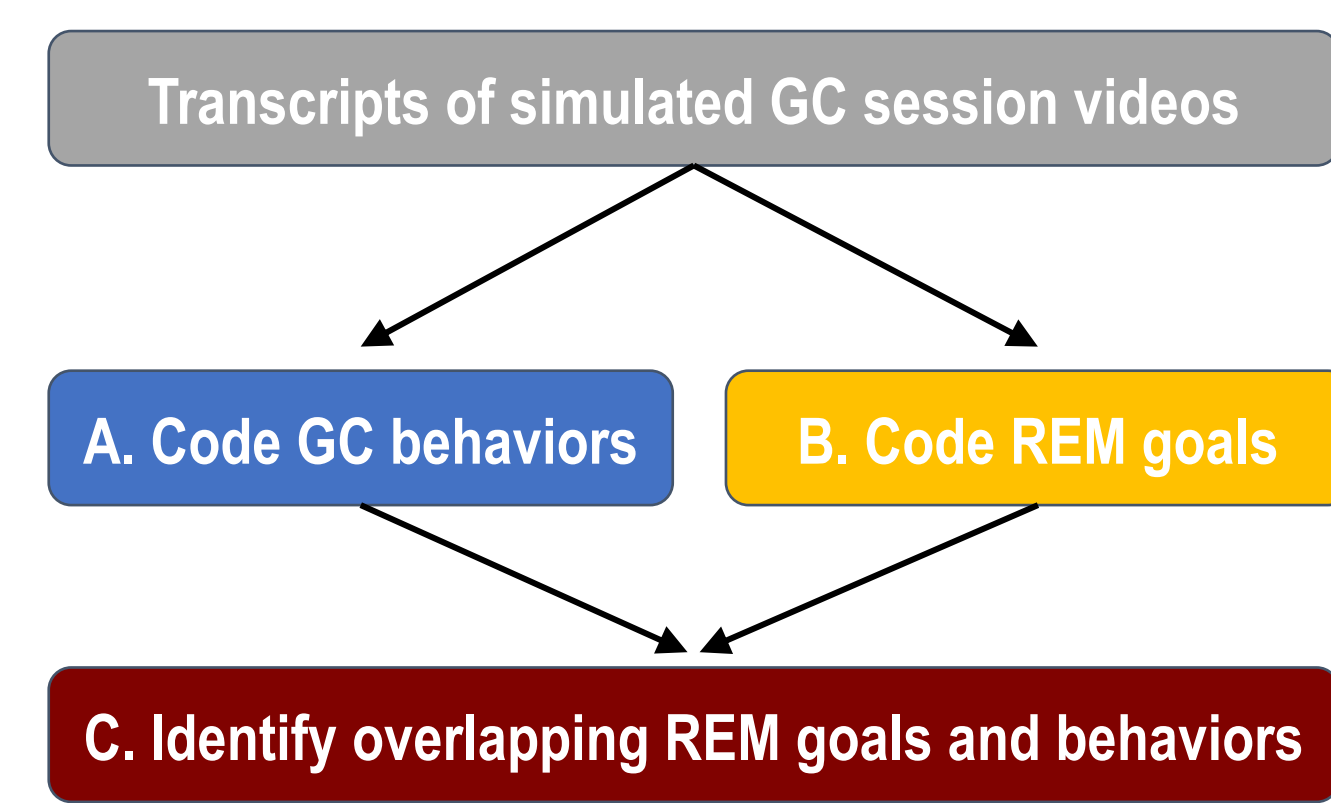
Transcripts of simulated GC session videos

A. Code GC behaviors

B. Code REM goals

C. Identify overlapping REM goals and behaviors

Figure 1. Overview of project procedure. A-C: 3 stages of data analysis.

Results

1. HSVRS Behaviors: Our first goal was to determine if a validated instrument of "helping behaviors" (HSVRS) could be used to identify GC behaviors in simulated session transcripts. Below you'll find a representative quote for each HSVRS behavior (left table), and the frequency of those identified behaviors (right table). Each column (right table) represents a single session transcript and shows the % of GC speech dedicated to each behavior during that session.

HSVRS Behavior	Representative Quote
Information	"So roughly 40 percent of people who have this particular Long QT type 1 syndrome, roughly 40 percent are asymptomatic." *(CR3)*
Content reflection	Patient: "What I need today is just to feel that…it's okay that I don't want to get tested." Counselor: "Okay, so you don't want testing." *(CN2)*
Affect reflection	"Okay, so that's very upsetting, obviously [that your mother's cancer has come back]." *(CN1)*
Closed question	"Have you told your family about your screening test result?" *(P1)*
Open question	"Can you tell me what you're nervous about?" *(CR2)*
Influence	"Okay, so obviously having had that experience [of a previous miscarriage] certainly makes you look at any testing that might have a [miscarriage] risk, perhaps, differently." *(P2)*
Advice	"Might be a good idea just to speak with [Cancer Legal Aid] about what their experience has been with health insurance companies and their discrimination, based on these specific genetic issues." *(CN3)*
Self-disclosure	[Regarding prenatal genetic testing for Long QT] "Some people, that's really important to them in making a decision about having a child." *(CR1)*
Self-involving	"I hope everything [with the amniocentesis for Down syndrome diagnosis] goes well." *(P1)*

HSVRS Behavior	% of total behaviors per session							
	Cancer			Cardiac			Prenatal	
Information	26	29	40	41	35	49	47	62
Content reflection	15	21	6	26	26	22	12	11
Affect reflection	28	18	30	9	13	3	15	9
Closed question	13	5	7	13	8	10	9	11
Open question	7	9	1	4	9	6	1	4
Influence	4	9	7	3	3	5	9	1
Advice	5	7	4	2	4	2	5	2
Self-disclosure	2	2	4	<1	<1	2	1	<1
Self-involving	<1	0	0	1.8	<1	1	1	<1
Total	100	100	100	100	100	100	100	100

Participant abbreviations: CN=cancer, CR=cardio, P=prenatal

2. REM Goals: Our second goal was to identify REM goals in each simulated session in order to (1) determine if observation of REM goals in simulated GC sessions further validates the applicability of REM goals to GC practice, and (2) to allow us to map HSVRS behaviors onto previously validated REM components—REM goals. You'll find select representative quotes (below left) and a binary identification of REM goals (below right). Goals were marked "present" or "absent" in each session. Goals were not quantified because it was beyond the scope of this project to standardize the length of GC speech dedicated to each REM goal. Each column represents a single simulated session.

Selected REM Goal	Representative Quote
Counselor presents genetic information	"Okay, so I'd like to suggest to you what the American Cancer Society recommends as well as a national preventive task force. They recommend a monthly breast self-exam for any woman who has a 25 to 50% chance of being a carrier or is actually a carrier. They recommend a mammogram and an MRI in six-month intervals." *(CN1)*
Facilitate collaborative decisions	"And some people say, 'Well, I'll try something like that. I will try to get a little bit more information for myself, and either then make a decision or then go with what I have.' It doesn't involve a risk, but it doesn't give you a yes or no answer. And I know you said you were a planner, and I don't know if that will be enough to help you…plan. *(P1)*
Counselor and patient know patient concerns	"So, can you tell me a little bit more about why you're feeling now's not the best time for you to do a genetic test?" *(CN3)*
Counselor characteristics positively in-fluence process	"Now if you're like me, statistics was not your favorite subject in school--" *(P2)*
Patient feels empowered and more in control	"Because the advantage of having this information in advance, the advantage of the diagnosis which probably doesn't feel very much like an advantage right now, but there is an advantage and that is that there's an opportunity to have some control…And there's an opportunity to institute some preventive care that we hope will minimize the impact." *(CR3)*
Recognize patient strengths	"You are somebody who I'm sensing is a very responsible father, as well as a family member that wants to make sure that whoever needs to know, needs to know." *(CR2)*

REM Goal	Presence (X) or absence of goal in a session							
	Cancer			Cardiology			Prenatal	
Counselor presents genetic information	X	X	X	X	X	X	X	X
Facilitate collaborative decisions	X	X	X	X	X	X	X	X
Counselor and patient know patient concerns	X	X	X	X	X	X	X	X
Integrate familial and cultural context into counseling relationship and decision	X	X	X	X	X	X	X	X
Counselor knows what information to impart	X	X	X	X	X	X	X	X
Patient's family dynamics are understood by counselor and patient	X	X	X	X	X	X	X	X
Genetic counselor and patient establish a bond	X	X	X	X	X	X	X	X
Adaptation	X	X	X	X	X	X	X	X
Empowerment	X	X	X	X	X	X	X	X
Establish working contract	X	X	X	X	X	X	X	X
Patient is informed	X			X	X	X	X	X
Patient gains new perspectives	X	X		X	X	X	X	X
Counselor characteristics positively influence process	X	X		X				X
Patient feels empowered and more in control				X	X	X	X	X
Recognize patient strengths				X	X	X	X	X
Patient self-esteem is maintained/increased								
Total (goals present in a session)	13	14	12	15	15	14	11	12

Participant abbreviations: CN=cancer, CR=cardio, P=prenatal

Results (cont.)

3. Mapping of HSVRS Behaviors onto REM goals: Our final goal was to anchor identified behaviors to a validated component of the REM—REM goals—in order to begin extending the REM. NVivo's matrix analysis (table below) was used to identify overlapping behaviors and goals. An "X" indicates that at least one GC used a behavior while addressing a particular REM goal. Matrices of individual sessions (not shown) show subtle variation while supporting the overall trend of multiple behaviors mapping to each REM goal.

REM Goals	HSVRS Behaviors								
	INFO	INFL	QC	SD	AD	C	QO	SI	A
Counselor presents genetic information	X	X	X	X	X	X	X	X	X
Facilitate collaborative decisions	X	X	X	X	X	X	X	X	X
Counselor and patient know patient concerns	X	X	X	X	X	X	X	X	X
Integrate familial and cultural context into counseling relationship and decision	X	X	X	X	X	X	X	X	X
Counselor knows what information to impart	X	X	X	X	X	X	X		X
Patient's family dynamics are understood by counselor and patient	X	X	X	X	X	X	X		
Genetic counselor and patient establish a bond	X	X	X	X	X	X	X	X	X
Adaptation	X	X	X	X	X	X	X	X	X
Empowerment	X	X	X	X	X	X	X	X	X
Establish working contract	X	X	X	X	X	X	X		
Patient is informed	X	X	X	X	X	X	X		X
Patient gains new perspectives	X	X	X	X	X	X	X		X
Counselor characteristics positively influence process	X	X	X	X	X				
Patient feels empowered and more in control	X	X	X	X	X				
Recognize patient strengths	X		X	X			X		

HSVRS Behavior abbreviations: INFO=information, INFL=influencing, QC=closed question, SD=self-disclosing, AD=advice, C=content reflection, QO=open question, SI=self-involving, A=affect reflection

Discussion

Findings

- All HSVRS behaviors were observed in the dataset at varying frequencies.
- Information giving was most prevalent (41.3%) and affect (feeling) reflections were least prevalent (0.7%).
- All analyzed REM goals, except "Counselor promotes maintenance of or increase in patient self-esteem," were identified in the dataset.
- The average REM goal was present in 7.1 sessions (Range: 4 to 8).
- Mapping analysis found an average of 7.1 different HSVRS behaviors used to accomplish each REM goal (Range: 2 to 9).

Conclusions

- Identification of HSVRS behaviors extends REM behaviors and provides preliminary support for the presence of HSVRS behaviors in genetic counseling practice
- Identification of most REM goals in most sessions further supports REM goals in observed practice. Some REM goals ("patient self esteem is maintained/increased") may be outside the scope of a 30-minute simulated GC session.
- Quantification of HSVRS behaviors supports a model of teaching and counseling practice that may prioritize patient education during 30-minute simulated GC sessions.

Limitations

- Patient speech was not analyzed.
- HSVRS behaviors do not include non-verbal skills (i.e., silence, physical and psychological attending).
- GC intentions were inferred to achieve REM goals coding.
- One REM goal was excluded from analysis: "Good counselor-patient communication."
- It was beyond the scope of this study to assess effectiveness of REM goals and HSVRS behaviors.

Recommendations

- Further research directions include (1) analysis of REM components in actual sessions conducted by GCs with diverse backgrounds and training experiences and (2) incorporation of GC and patient feedback to assess intent and effectiveness.
- Observation of HSVRS in expert GC practice supports training and education in these helping skills.

References

[1]McCarthy Veach, P., et al. Bartels, D. M., & LeRoy, B. S. (2007). Journal of Genetic Counseling, 713-728. [2]Ash, E. (2017). Journal of Genetic Counseling, 26, 300-311. [3]Hartmann, J., McCarthy Veach, P., MacFarlane, I., & LeRoy, B. (2015). Journal of Genetic Counseling, 24, 225-237. [4]Redlinger-Grosse, K., McCarthy Veach, P., Cohen, S., LeRoy, B. S., MacFarlane, I. M., & Zierhut, H. (2016). Journal of Genetic Counseling, 25, 239-257. [5]Redlinger-Grosse, K., McCarthy Veach, P., LeRoy, B. S., & Zierhut, H. (2017). Journal of Genetic Counseling, 26, 1372-1387. [6]Shugar, A. (2017). Journal of Genetic Counseling, 26, 215-223. [7]Williams, S. R., Berrier, K. L., Redlinger-Grosse, K., & Edwards, J. (2017). Journal of Genetic Counseling, 26, 337-354. [8]Reiser, C. A. (2011). JEMF Master Genetic Counselor Series. NSGC. Retrieved April 4, 2021. [9]Danish, S. J., D'Augelli, A. R., Hauer, A. L., & Conter, J. J. (1980). Helping Skills: A Basic Training Program, Volume 2. Human Sciences Press. *Introduction photos by https://unsplash.com/@amyhirschi @javotreuba @thisisengineering