

Fall 2021

GS11 1082: Psychosocial Issues in Genetic Counseling I

Credit Hours: 2

Meeting Location (Building/Room # or WebEx/Zoom):

McGovern Medical School B.625

Program Required Course: Yes No

Approval Code Yes No

(If yes, the Course Director or the Course Designee will provide the approval code.)

Audit Permitted: Yes No

Classes Begin: August 18, 2021

Classes End: December 08, 2021

Final Exam Week: December 08, 2021

Class Meeting Schedule:

Day	Time
Wednesday	10:00 a.m.-12:00 p.m.

Course Director:

Claire N. Singletary, MS, CGC

Program Director, UT Genetic Counseling Program

Professor, Pediatrics and Obstetrics/Gynecology

McGovern Medical School, UTHealth

Email Address: Claire.N.Singletary@uth.tmc.edu

Contact Number: 713-486-2294

Course Co-Director/s:

Jennifer Czerwinski, MS, CGC

Associate Director, UT Genetic Counseling Program

Associate Professor, Obstetrics, Gynecology, Repro.Science

McGovern Medical School, UTHealth

Email Address: Jennifer.L.Sherrill@uth.tmc.edu

Contact Number: 713-486-2290

NOTE: Office hours are available on request. Please email me to arrange a time to meet.

Instructor/s:

Claire & Jen

Course description:

The psychosocial component of genetic counseling is often one of the most difficult for students to master due to the perception that psychosocial constructs are less concrete. This class is designed to arm first year genetic counseling students with the knowledge and background needed to excel in psychosocially charged situations as well as to provide practice with examples and role play scenarios.

Textbook/Supplemental Reading Materials:

- Uhlmann WE, Schuette JL, Yashar BM (2009) A Guide to Genetic Counseling, ISBN# 9780470179659
- Veach, LeRoy, and Callanan (2018) Facilitating the Genetic Counseling Process, ISBN# 978-3319747989
- LeRoy BS, McCarthy Veach P, Bartels DM (2021) Genetic Counseling Practice: Advanced Concepts and Skills, ISBN# 9781119529859
- Weil (2000) Psychosocial Genetic Counseling, ISBN#0195120663

Course Objective/s:

Upon successful completion of this course, students will have acquired foundational psychosocial genetic counseling skills, including establishing a mutually agreed upon agenda, employing active listening and interviewing skills to identify, assess, and empathically respond to future clients, and facilitating informed decision making.

Specific Learning Objectives:

1. Demonstrate eliciting client expectations and establish a mutually agreed upon genetic counseling agenda
2. Practice employing active listening and interviewing skills to identify, assess, and empathically respond to client concerns
3. Describe a range of genetic counseling skills and models to facilitate informed decision making and adaptation to genetic risks or conditions, such as tailoring, flexibility, and risk perception
4. Promote and facilitate client-centered, informed, non-coercive and value-based decision making
5. Recognize the importance of advocating for individuals, families, communities and the genetic counseling profession
6. Effectively educate clients about genetics/genomic based on their needs, characteristics and circumstances

Student responsibilities and expectations:

Students enrolled in this course will be expected to perform the following activities each week.

1. Read, process the assigned readings prior to each class
2. Actively engage in weekly class discussions
3. Participate in role-plays in class
4. Prepare for and take course quizzes based on course lectures/ readings.
5. Attend and participate in class field trips
6. Develop unique work on assignments and submit in a timely fashion (see grading)

Students are expected to complete all assigned reading material prior to class. While you may work and discuss all course materials and assignments in groups, all final products must be your own. Plagiarism and failure to properly cite scientific literature and other sources will not be tolerated and are grounds for dismissal from the course and further GSBS disciplinary action. Cheating or engaging in unethical behavior during examinations (quizzes and final) will be grounds for dismissal from the course without credit and further GSBS disciplinary action. Attendance is mandatory for all assigned classes. Missing more than one class for any reason (excused or unexcused) will result in a reduction in the student's final letter grade by one full letter grade. Exceptions will only be made for an illness with a doctor's note. Being tardy to two classes by more than 5 minutes is considered an unexcused absence.

Grading System: Letter Grade (A-F); 90-100 A, 80-89 B, 70-79 C, 60-69 D, <60 F

Student Assessment and Grading Criteria :

Tailoring/Risk Group Assignment (15%)	Present visual aid and act out use of a variety of learning styles - See below in assignments for details
Working with women with ID fact sheet (10%)	Single page, at least 10pt font, at least 0.5inch margins, bullet points or other easy to access format
HD immersion and summary reflection (15%)	Journal entries at least 2 sentences per day, no more than two paragraphs per day; summary reflection should be one page; use at least 10pt font
Psychosocial Library Readings/Summary (10%)	Single page, at least 10pt font, at least 0.5inch margins, bullet points or other easy to access format; one for each book
Support group assignment (10%)	Half to full page, at least 10pt font, at least 0.5inch margins, bullet points or other easy to access format for each group; single page summary
Advocacy/outreach participation (5%)	Attend the scheduled field trip(s) to Rise, The Center, and Celebration Company
Quiz (15%)	Multiple choice quiz in Canvas
Final Exam (15%)	Standardized Patient Role Play Exam and Self-Assessment
Participation and/or Attendance (5%)	Participate in discussion by adding in your point of view at least once per class period

CLASS SCHEDULE

Day/Date	(Hr)	Lecture Topic	Lecturer/s
8/18	2	Getting started = know your client, building rapport 1. Uhlmann, Ch 3 (p71-76) 2. Uhlmann, Ch 5 (p135-137 and p155-166) 3. McCarthy-Veach Ch 2 [<i>bring this book to class</i>]	Claire Singletary
8/25	2	Contracting, agenda setting and open-ended questions 1. McCarthy Veach Ch 5, 6 2. Uhlmann, Ch 3 p76-80 3. Microskills Pyramid and Intentional Questioning	Claire Singletary
9/1	2	Attending Skills; Nonverbal Cues 1. McCarthy Veach, Ch 3 2. Uhlmann, Ch 3 p80-90	Claire Singletary
9/8	2	Primary Empathy, Reframing, Normalizing 1. McCarthy Veach 4	Claire Singletary

		2. Optional additional reading: Weil, Ch 3 p56-68	
9/15	2	Flexibility and Tailoring I: Word Choice, Numeracy <ol style="list-style-type: none"> Uhlmann, Ch 6 to p 196 and Ch 7 to p 212 (bring this book to class) Gates EA (2004) Communicating Risk in Prenatal Genetic Testing, <i>J Midwifery Womens Health</i>, 49(3), 220-227. Ch 4, Leroy, <i>Genetic Counseling Practice: Advanced Concepts and Skills</i> Ch 7 (p 173 – 178, 184 - 189), McCarthy Veach <i>Facilitating the Genetic Counseling Process</i> <p>Complete VARK – bring completed questionnaire to class https://vark-learn.com/the-vark-questionnaire/</p>	Jen Czerwinski
9/22	n/a	No Class Meeting – NSGC Time allocated to field trips to Rise School, the Center, Celebration Company	
9/29	2	Flexibility and Tailoring II: Working with adolescents and individuals with intellectual disability <ol style="list-style-type: none"> Weil, Ch 6 p 199-213 and Leroy, Ch 10 Book by Finucane, available through the Program 	Jen Czerwinski
10/6	2	Flexibility and Tailoring III: Decision Making <ol style="list-style-type: none"> Uhlmann, Ch 7 224 - 243 Ch 7 (p 190 – 201), McCarthy Veach <i>Facilitating the Genetic Counseling Process</i> Tversky A & Kahneman D (1981) The Framing of Decisions and the Psychology of Choice, <i>Science</i>, 211(4481), 453-358. Complete survey (by 8 am on 10/05) https://uthtmc.az1.qualtrics.com/jfe/form/SV_ahFeDo86U5Y4sWF 	Jen Czerwinski
10/13	2	Difficult Patients: Coping, Resistance, Transference <ol style="list-style-type: none"> McCarthy Veach Ch 9 McCarthy Veach Ch 12 (p 329-333) 	Claire & Jen
10/20	2	Difficult Patients: Countertransference <ol style="list-style-type: none"> McCarthy Veach Ch 12 (p 333-351) Complete the countertransference checklist on pg 355 in MV/copy on the drive. 	Claire & Jen
10/29 2-4 [alt date for ACGC site visit]	2	Breaking Difficult(Bad) News <ol style="list-style-type: none"> Weil Ch 6 p161-8 Dent KM & Carey JC (2006) Breaking Bad News in A Newborn Setting: Down Syndrome as a Paradigm, <i>Am J Med Genet</i>, 142C: 173-179. 	Claire Singletary

		<ol style="list-style-type: none"> 3. Sheets et al (2011) Practice Guidelines for Communicating a Prenatal or Postnatal Diagnosis of Down Syndrome: Recommendations of NSGC, <i>J Genet Couns</i>, May. 4. Brasington CK (2007) What I Wish I Knew Then...Reflections from Personal Experiences in Counseling about Down syndrome, <i>J Genet Couns</i>, 17, 7nob31-734. 5. Resta, Bob – I didn't want to tell you poem 	
11/3	2	Breaking Difficult(Bad) News II: Role Plays <ol style="list-style-type: none"> 1. Baile, WF et al (2000) SPIKES – A Six-Step Protocol for Delivering Bad News: Application to the Patient with Cancer, <i>The Oncologist</i>; 5: 302-311 2. Fonda Allen JS (1995) Genetic Counseling After Abnormal Prenatal Diagnosis: Facilitating Coping in Families Who Continue Their Pregnancies. <i>J Genetc Couns</i>, 4:251-264. 	Claire & Jen
11/10* 9-12 time slots in SCSC TBD	1	Standardized Patient Exam in the SCSC: Breaking Difficult News	Claire & Jen
11/17	2	Life Cycle; Person First Language; Lived Experience <ol style="list-style-type: none"> 1. Weil, Chs 1 and 2 to p34. 2. <u>Welcome to Holland</u> - by Emily Perl Kingsley 3. <u>Holland Schmolland</u> by Laura Kreuger Cra 4. Person First Language Sheet & FAQ by Kathie Snow 	Claire Singletary
11/19 1-3		Psychosocial Quiz (on canvas – bring ipads to class), (0.5 hr) Psychosocial Library (1.5 hr) Group discussion of <u>There is No Good Card for This</u> Individual 5 min presentations for each additional book	Jen & Claire
11/24		NO CLASS – Thanksgiving Break	
12/1	3.5	Huntington Disease Immersion Exercise Presentations (1.5 hr) Huntington Assignment Discussion in class Support Groups (1 hr) Support group rationale presentation Class presentations and discussion	Jen Czerwinski Claire Singletary
12/8		NO CLASS (see class on 11/19)	

Assignments:

Date	Pts	Description															
9/15	15	<p>Tailoring & Risk Perception - Group Assignment (15 pts)</p> <ol style="list-style-type: none"> Complete the VARK: bring completed questionnaire to class http://www.vark-learn.com/english/page.asp?p=questionnaire Studies show that adults tend to prefer to learn in one of three main domains: auditory, visual, and kinesthetic/tactile. Since adults prefer to learn in different formats, it follows that patients will prefer to learn risk information in different ways. Therefore, genetic counselors need different tools at their disposal to explain risk. <table border="1" data-bbox="344 625 1495 1606"> <tr> <td data-bbox="344 625 651 705">Auditory - listening and discussing</td> <td data-bbox="651 625 1068 705">Visual - seeing</td> <td data-bbox="1068 625 1495 705">Kinesthetic - learn by doing/touching/tactile</td> </tr> <tr> <td data-bbox="344 705 651 863">Q&A, songs, acronyms, metaphors, definitions</td> <td data-bbox="651 705 1068 863">Diagrams, charts, color, flowchart, maps, photo</td> <td data-bbox="1068 705 1495 863">puzzle, building things, toys, props, role play</td> </tr> <tr> <td data-bbox="344 863 651 1020">Identify sounds related to an experience</td> <td data-bbox="651 863 1068 1020">Have a sharp, clear picture of an experience</td> <td data-bbox="1068 863 1495 1020">Develop a strong feeling towards and experience</td> </tr> <tr> <td data-bbox="344 1020 651 1293">I hear you clearly, I want you to listen... This sounds good</td> <td data-bbox="651 1020 1068 1293">Do you make pictures in your head Do you have visual images in your head as you are talking and listening to me? Can you see what I am saying?</td> <td data-bbox="1068 1020 1495 1293">Do you feel what you are saying? Are you in touch with what I am saying?</td> </tr> <tr> <td data-bbox="344 1293 651 1606">How do you hear this situation going? What do you hear that is stopping you? Sounds heavy.</td> <td data-bbox="651 1293 1068 1606">How do you see the situation? What do you see stopping you? This looks good. Do you see what I am showing you?</td> <td data-bbox="1068 1293 1495 1606">How do you feel about this situation? I'm getting a handle on this material. Let's move together. Does what I am putting you in touch with feel right? Sounds heavy.</td> </tr> </table> <p>Since we most often start with a verbal/auditory explanation, you and your genetic counseling colleagues (other members of your assigned group) have been asked by your supervisor to create a visual and a kinesthetic way to creatively convey risk information for your patient</p> <p>Each group will present a visual AND a kinesthetic risk explanation in front of the class. Please get together virtually or in-person to prepare your presentation. Presentations will need to adhere to social distancing guidelines.</p>	Auditory - listening and discussing	Visual - seeing	Kinesthetic - learn by doing/touching/tactile	Q&A, songs, acronyms, metaphors, definitions	Diagrams, charts, color, flowchart, maps, photo	puzzle, building things, toys, props, role play	Identify sounds related to an experience	Have a sharp, clear picture of an experience	Develop a strong feeling towards and experience	I hear you clearly, I want you to listen... This sounds good	Do you make pictures in your head Do you have visual images in your head as you are talking and listening to me? Can you see what I am saying?	Do you feel what you are saying? Are you in touch with what I am saying?	How do you hear this situation going? What do you hear that is stopping you? Sounds heavy.	How do you see the situation? What do you see stopping you? This looks good. Do you see what I am showing you?	How do you feel about this situation? I'm getting a handle on this material. Let's move together. Does what I am putting you in touch with feel right? Sounds heavy.
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		<p>1 – Cancer – Lifetime risk of 27-55% for ovarian cancer with a BRCA1 or 2 mutation Team A - Emily, Tessa Team B - Cindy, Jack</p> <p>2 – Prenatal/Medical Genetics – Chance for a Fragile X carrier (of 75 repeats) to have a child with Fragile X syndrome (31% risk of expanding to a full mutation) - focus on risk of child being affected with Fragile X, not the risk of being a premutation carrier Team C - Latonya, Maddi, Jasmine Team D - Erin, Yusra, Jordan</p>
9/29	10	<p>Working with women with intellectual disability fact sheet Read <i>Working with Women Who Have Mental Retardation: A Genetic Counselors Guide</i> by Brenda Finucane. Please make yourself one page front/back reference item of your choosing with details on tips for counseling women with mental retardation. Topics to include in your fact sheet include IQ ranges, developmental characteristics of preoperational stage, what is needed for informed consent, inelegant goals, and strategies for genetic counseling.</p>
11/19	10	<p>Psychosocial library reading assignment and summary Everyone will read: <u>There is No Good Card for This</u> (Kelsey Crowe and Emily McDowell) <i>**no more than two students should read the same book – sign up on line after first class**</i> Choose 1 additional book from one of these three sections: prenatal, pediatric, and adult/cancer. Summarize the relevant points from each book that you read in either bullet point or paragraph format. The summary should be no shorter than one page and no longer than two pages. Students who turn in the completed assignment on time and participate in the class discussion with knowledgeable points about their works will receive full credit. You are encouraged to read additional selections on your own in the future and are welcome to check out books from the suite at anytime. The summaries are due on the day we discuss books in class.</p>
dates TBD - by 12/1	5	<p>Advocacy/Outreach: Field Trips to Local School and Residential Facility <i>*due to pandemic restrictions, alternative methods for learning about these facilities may be organized. An opportunity to attend in person may be scheduled for a later semester.</i></p> <ol style="list-style-type: none"> 1. The Rise School http://www.riseschool.org -tour the Rise school and spend the morning in an integrated preschool classroom. PT, OT, Speech and other therapy is on site. Located across 288 from the TMC at 5618 H. Mark Crosswell Jr St, Houston, TX 77021 https://www.youtube.com/watch?v=Efu65ohanqw&t=17s 2. https://www.riseschool.org/ 3. The Center –http://thecenterhouston.org/services/residential-services tour the facility, including residence buildings and workshops. Carpooling is encouraged.

		<p>Located near NRG Stadium for the day facilities at 9310 Kirby, Suite 900 Houston TX 77054 https://www.youtube.com/watch?v=VrCZKEF33yE https://thecenterforpursuit.org/</p>
12/1	10	<p>Support Groups</p> <ol style="list-style-type: none"> 1. “Live” Support group meeting: attend one meeting of a live support group either in person or virtual synchronous. Consult the drive for local support group information or research on your own. Please call/email the contact number/individual to verify the meeting location, time, and topic and to ask permission to attend the meeting. At the meeting, you should observe the group dynamics. Speak with the group contact person and ask for their comments on the organization of the support group (i.e. how they made it work, what didn’t work, how formal/informal, etc.). 2. Asynchronous support group: join an online chat group/yahoo group/discussion board (asynchronous) for a genetic condition. Seek appropriate permission to join the group. Follow the discussion thread for at least one month. Observe how the group responds to posts. Is inaccurate information taken down? Corrected? Is medical advice given? Does a health care provider monitor the group? 3. Summary: Turn in a one page bulleted summary of your experience and to present an oral summary of your experience in class. Compare and contrast the in person/virtual and online environments. What types of coping mechanisms, stages of grief, etc, did you observe? What type of group might you personally prefer? How will this experience change how you refer patients to support groups?
12/1	15	<p>Huntington disease role immersion exercise</p> <p>Watch one of three assigned documentaries on HD:</p> <ol style="list-style-type: none"> 1. The Lion’s Mouth Opens - Latonya, Erin, Emily, Cindy https://www.youtube.com/watch?v=rX8zeo4ieLY 2. Twitch – Maddi, Yusra, Tessa (available on DVD to check out from Claire’s office) 3. The Gene: An Intimate History - Jasmine, Jordan, Jack Disc 1: 1:08:00 - 1:26:45 and 1:42:00 - 1:50:15 (available on DVD to check out from Jen’s office) <p>Keep a daily diary and write a summary reflection: Assume the persona of an individual who is at risk for Huntington Disease. Assign a parent to have HD and a backstory. Consider the impact within your personal situation (married, dating, single, siblings, etc.). This assignment will span the weeks of Nov 1 to Nov 12. During the first week you will plan your genetic counseling appointment, have</p>

		<p>HD DNA testing performed on Nov 2, receive your results on Nov 5, and journal about the impact of the results until Nov 11. On the final day (Nov 12), consider and summarize, in writing, how this exercise has impacted how you will practice as a genetic counselor and/or how you view your patients. Please do not discuss your feelings or experience with each other until we have the interactive presentations. Submit your finished diary via email to Jen by Nov 19. We will discuss your thoughts and feelings about the exercise in class on Dec 1.</p>
11/10	15	<p>Exam – Standardized Patient Scenario in the SCSC</p> <p>The final exam will take place on Nov 10 in the Surgical and Clinical Skills Center. Approximately two weeks prior to the encounter you will receive additional information regarding the case so that you may prepare the informational aspects. You will be graded on your ability to employ the basic psychosocial skills that are discussed in this course as well as to provide baseline patient education. Your session will be viewed by the course instructor(s) and an additional genetic counselor</p>
11/19	15	<p>Psychosocial Quiz</p> <p>You will be given a quiz over the psychosocial concepts discussed over the course of the semester. Questions will be presented in a vignette style with multiple choice answers where you are asked to select the ‘next best step’. The quiz will likely consist of 15 questions on Canvas.</p>