

**GENC 5251 and GENC 5351
Genetic Counseling Ethics I and II
Face-to-Face and Interactive Video**

University of Arkansas for Medical Sciences
College of Health Professions

Department of Genetic Counseling

1 Semester Credit
15 lecture hours

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1.0 General Information

Ignorance of the GENC 5251/5351 course policies outlined in this syllabus, the Department of Genetic Counseling Handbook or posted on the course site in the "Syllabi" folder is not an excuse for failure to comply with these policies.

NO AUDIO OR VIDEO RECORDINGS OF THIS CLASS ARE PERMITTED.

1.1 Catalog Description (GENC 5251/5351)

Methods of ethical case analysis through lecture, demonstrations, and problem-based learning. Focus will be placed on cases/situations that genetic counselors will encounter in everyday employment and other professional areas.

1.2 Course Rationale

This course will introduce students to issues in biomedical and genetics ethics, such as patient autonomy, conflicts of interest, professional ethics, and values in genetic decision-making. Through a variety of presentations and group discussions, students will become familiar with the National Society of Genetic Counselors' Code of Ethics. It will aid the student in recognizing specific professional duties that genetic counselors have toward their patients, themselves, their colleagues, and society at large. Completion of the course is required for the program, and aspects fulfill very specific objectives set forth by the Accreditation Council for Genetic Counseling (ACGC).

1.3 General Course Objectives

Upon completion of this course and as prescribed by the ACGC, the student will be able to:

- Demonstrate an understanding of the psychosocial, ethical, and legal issues related to genetic counseling encounters (I.2.a).
- Recognize one's own values and biases as they relate to genetic counseling (II.11.a).
- Follow the guidance of the National Society of Genetic Counselors Code of Ethics (IV.17.a).
- Recognize and respond to ethical and moral dilemmas arising in genetic counseling practice and seek outside consultation when needed (IV.17.b).
- Identify and utilize factors that promote client autonomy (IV.17.c).
- Recognize and acknowledge situations that may result in a real or perceived conflict of interest (IV.17.e.).
- Identify and clearly express the central ethical problem(s) for ethically challenging cases or policies.
- Express a well-developed position in response to the ethical problem(s).

- Provide relevant and well-organized factual and normative support for an ethical position.
- Discuss the strengths and weaknesses of substantive alternatives to a chosen position.
- Explain the important ethical concerns or principles for healthcare ethics.

2.0 Instructional Methodology

2.1 General Techniques

This course will be delivered in a classroom (face-to-face) setting, as well as via interactive video for off-site students and instructors. In addition, assignments and learning resources are available online via Blackboard learning management system. Instructors and students may join the class via interactive video when prior arrangements are made and with approval from the Course Director. Active student participation is required, both in the classroom setting (or via video when applicable) and for any online activities. Instructional techniques for this course include lecture/discussion format and team-based learning.

2.2 Resource--Based Techniques

This course incorporates the following resource-based techniques: PowerPoint presentations and video clips within Blackboard or other online resources; computer assisted instruction; mediated self-instruction; conference calls; interactive video; and campus lectures.

3.0 Instructional Materials/Supplies

3.1 References--Print Materials

All materials will be available on Blackboard. There is no book to purchase for this course.

For discussion posts and short papers, students may also search the medical and ethics literature for additional articles and sources.

3.2 References--Audiovisual Materials

There are no audiovisuals required for purchase by the student for this course. Audiovisuals utilized by the instructor during this course will be announced at the beginning of the class period. Students who would like to view the audiovisual again during non-class time should contact the instructor for the location of the audiovisual and/or to make arrangements for a second viewing.

3.3 Computer Requirements

The student must have a computer that has Internet connectivity with a Web browser that is compatible with the current learning management system. Students must have prior permission to connect to class via interactive video. On quiz days, students must have their internet-capable computer with them; please discuss any concerns fulfilling this requirement with the Course Director immediately. Students should refer to the Department of Genetic Counseling Handbook for computer requirement specifications.

3.4 Technical Assistance Notification

The UAMS Academic Affairs Student Success Center provides assistance with laptops and mobile devices. A student support/technology analyst is available to assist with various technology issues, from connecting to the wireless network to troubleshooting possible hard drive issues. The analyst is located on the 3rd floor of the Library (ED II 3/108) from Monday through Friday from 8AM to 5PM. Assistance is also available remotely. Phone: 501-526-6003 for help with issues on any of the following: PC, Mac, Linux, Android, iPhone, Windows Phone, or Blackberry.

4.0 General Evaluation Procedures

4.1 Student Evaluation Procedures

Students will be evaluated based on Blackboard discussion posts, quizzes, short papers, and a final exam.

Evaluation Type	Description	% of <u>total grade</u>
DISCUSSION POSTS	Before most classes, students are expected to make a <i>substantive</i> discussion post related to the readings that are assigned for the <i>following</i> class day. There will be specific prompts on some days provided by the Course Director. The purpose is to encourage active reading and preparation prior to class. The posts will be assigned full points (10), half points (5), or no points (0) based on how well the student demonstrated their understanding of the reading and reflected thoughtfully on it. Each post should be at least one paragraph (6-8 sentences). All the posts are weighted equally (so each is worth 1.875% of the total grade).	15
QUIZZES	Quizzes will cover any concepts previously discussed during the course or assigned readings for the class during which the quiz	15

	occurs. There are 3 quizzes, all weighted equally (so each is worth 5% of the total grade). Students receive credit for completing the quizzes during class.	
SHORT PAPERS	The prompts and instructions for short papers will be available on Blackboard. Students will be asked to write 2 papers of 1000 words each on a topic related to the readings and case discussions. The papers are weighted equally (so each is worth 15% of the final grade).	30
FINAL EXAM	Final exam will cover key terminology and ethical concepts covered during the course. This is a written examination and closed book.	40
	Total	100

Grading is on the following scale:

90-100%.....A
80-89%.....B
70-79%.....C
60-69%.....D
<60%.....F

Submitting Assignments Electronically

- All assignments need to be submitted electronically on the BB course site, **unless otherwise instructed.**
- Assignments can be submitted using Microsoft Word, Excel, PowerPoint or other presentation software (with approval from the Course Director), **unless otherwise instructed.**

Assignment Due Dates

- **All due dates for discussion posts and short papers are listed in this syllabus with reminders on Blackboard.** Full points will only be possible for discussion posts that are submitted by the deadline; delinquent discussion posts can only receive partial or no points. Failure to submit short papers by the announced due date and time will result in a 10% penalty for every 24 hours the assignment is late, unless otherwise stated in the assignment instruction (a short paper turned in 12 hours late will receive 5% deduction and so forth). **Students are encouraged to submit their assignments prior to the deadline so that if technical**

difficulties are encountered, they can be addressed prior to the assignment deadline. Students should communicate any issues with submitting assignments on time promptly with the Course Director, and there may or may not be make-up options at the discretion of the Course Director.

- If a student misses a quiz, the student may have the option of taking a separate quiz in its place by making prompt arrangements with the Course Director, but only if the absence is considered excused by the Course Director.

Technical Problems

- In the event of technical problems with Blackboard, assignments can be sent to the Course Director via email. To ensure that your email is not identified as spam or junk mail, you should use the following format in the subject line: ***Student's Last name, GENC 5251/5351 and the name of the assignment. The assignment MAY not be graded if the subject line is not properly completed.***

e.g. **Smith GENC 5251/5351 Short Paper 1**

- If technical problems prevent you from submitting your assignment electronically, either through the course site or to the Course Director's email, call the Course Director. If you leave a message, remember to include a phone number where you can be reached.

Illness or Emergency

- If you have an illness or emergency prior to an assignment deadline and need a due date extension, contact the Course Director prior to the assignment deadline, if possible, or as soon as possible. In such cases, documentation regarding the illness or emergency may be required for the due date extension to be considered. The due date extension may be granted or denied at the discretion of the Course Director. Students must discuss problems with their ability to turn in other required assignments by the due date with the Course Director.

Graded Assignments

- Feedback on graded assignments will be posted in BB or sent over email to students.
- If you need to discuss your grade or the feedback you received on an assignment, contact the Course Director.

Grade Adjustment

- Students may select 1 assignment (discussion posts or short papers only!) during the course to redo, if the student is unhappy

with his/her grade on the submitted assignment. To do this, the student has up to one week to request permission to redo the assignment if possible or complete a new assignment. An assignment can only be revised once. This option does not apply to other points/grades for the course. Revised work must be completed within one week of the granted permission. Final grade for the assignment will be based on the quality of work for the revised submission.

Virus Free Assignments

- Students are responsible for ensuring that their assignment files are virus-free. Assignments that fail the instructor's virus checker software will not be opened or accepted. Should this occur, you will be notified via email and given 24 hours to submit a virus-free version of the assignment. If this happens a second time with the same assignment, the student will not receive credit for the assignment.
- If an assignment is not accepted because this policy is not adhered to, no credit will be given for the assignment. It will need to be resubmitted in a virus-free format before future assignments will be graded for credit.

4.2 Instructor Evaluation Procedures

While comments regarding the course and instruction are welcomed by the instructor at any time, students will be given the opportunity to complete CHP course and instructor evaluations. Your participation in this evaluation is appreciated.

4.3 Performance, Lab, Clinic, and Project Evaluation

Details will be provided on BB or by the Course Director.

4.4 Makeup and Retake Examinations

If a student misses the final examination, the student must contact the Course Director. If the absence is due to an illness or emergency, documentation regarding the illness or emergency will be required for a makeup examination to be considered. A request for a makeup examination may be granted or denied at the discretion of the Course Director.

5.0 General Procedures

The course consists of lectures, team-based learning activities, and debriefing sessions. Schedule changes may occur to accommodate other learning activities, holidays, conferences or other conflicts. Otherwise, class will be on Wednesdays from 3:30-4:30.

6.0 Class Attendance/Conduct/Dress Policy

6.1 General Remarks

In order to maximize learning opportunities, attendance will be required for all class activities.

Students are expected to actively engage in their education by attending and/or participating in class activities (face-to-face or at a distance). Faculty will monitor their students' active participation. It is the responsibility of the faculty to report any student who has not attended or actively participated in learning activities for a period of two weeks to the Registrar. The Registrar or the Associate Dean for Academic Affairs will attempt to contact the student to learn the reason for his/her lack of participation. If a satisfactory reason is not presented and the student does not actively engage in learning activities in the class(s) in a three-week period, the student will be administratively dropped from the class/es. If all classes are dropped, the student is administratively withdrawn from the CHP program.

6.2 Session Absence Grading Effects

Students are expected to be diligent in the pursuit of their studies and in their class attendance. Students are responsible for notifying the Course Director when their absence will not allow them to participate in one or more class activities. Students are expected to notify the Course Director when their absence will prevent them from accessing Blackboard or email for more than 24 hours, Monday through Friday (except holidays). Students have the responsibility of making arrangements satisfactory to the instructor regarding all absences. Such arrangements should be made prior to the absence if possible.

Any unexcused absence will result in lowering the final course grade by five percentage points (5%) for each unexcused absence.

6.3 Session Tardiness Grading Effects

Students will not be allowed to take a quiz after it has started. If a student leaves during a quiz, s/he cannot return until the quiz is complete. This may be viewed as either an excused or unexcused absence depending on the circumstances.

6.4 Conduct/Dress

Students are expected to treat each other and instructors in a civil, polite, and professional manner. Students are not expected to "dress up." Normal class attire is acceptable. For more information regarding the dress code, please refer the most recent version Department of Genetic Counseling Student Handbook.

7.0 Due Dates/Deadlines

See Blackboard and section 8.2 for all assignments, quizzes, and exams.

8.0 Sessions Schedules

8.1 General Remarks

Class will *generally* meet on Wednesdays from 3:30-4:30 pm in CHP 5.134 and IVN connections, but refer to below schedule for exact dates of each class.

8.2 Tentative Sessions Schedule

<i>Class Day</i>	<i>Topic</i>	<i>Reading to Be Completed by Start of Class</i>	<i>Assignment (w/ Deadline)</i>
August 14 th	Introduction		
August 21 st	Introduction to Ethics	"What Is Morality?" by Rachels & Rachels "Four Questions of Ethics" by Veatch NSGC Code of Ethics	Discussion post (due by end of day 8/20)
August 28 th	Principles of Bioethics	"Respect for Autonomy" by Beauchamp & Childress "Justice" by Beauchamp & Childress	Quiz (in class)
September 5 th (instead of 9/4)	Principles of Bioethics	"Nonmaleficence" by Beauchamp & Childress "Beneficence" by Beauchamp & Childress	Quiz (in class)
September 11 th	Values in Genetics	<i>From Chance to Choice: Genetics & Justice</i> by Buchanan et al. (excerpt) "Genetic Counseling: Values That Have Mattered" by Sorenson	Discussion post (due by end of day 9/10)
September 18 th	Uncertainty	"Known Unknowns" by Newson et al. "May the Odds Be Ever in Your Favor?" by Reynolds	Discussion post (due by end of day 9/17)
September 25 th	Disability	"The Relationship between the Genetic Counseling Profession and the Disability Community: A Commentary" by Madeo et al. "The Case for Conserving Disability" by Garland-Thomson	Discussion post (due by end of day 9/24)
October 2 nd	Nondirectiveness	"Psychological Aspects of Genetic Counseling. XI. Nondirectiveness Revisited" by Kessler (cont'd on next page)	Discussion post (due by end of day 10/1)

(October 2 nd , cont'd)		<p>"Psychosocial Aspects of Genetic Counseling in the Post-Nondirective Era" by Weil</p> <p>"Patient Autonomy and Value-Neutrality in Nondirective Genetic Counseling" by Wachbroit & Wasserman</p>	
October 9 th	Nondirectiveness	"Vulnerability in Genetic Counseling and the Ground of Nondirectiveness" by Deem	Short paper (due 10/12 by 12 pm)
October 16 th	Conflicts of Interest	<p>"Conflicts of Interest in Genetic Counseling: Acknowledging and Accepting" by Stoll et al.</p> <p>"Conflicts of Interest in Genetic Counseling: Addressing and Delivering" by Iacoboni et al.</p> <p>"Conflicts of Interest in Genetic Counseling: Persistent Underlying Questions" by Stoll et al.</p>	Quiz (in class)
October 23 rd	Incidental Findings	<p>"These Are Not the Genes You Are Looking For" by Coughlin</p> <p>ACMG Recommendations for Reporting of Incidental Findings in Clinical Exome and Genome Sequencing</p>	Discussion post (due by end of day 10/22)
October 30 th	Prenatal Testing	<p>"Genetic Dilemmas and the Child's Right to an Open Future" by Davis</p> <p>"The Uncertain Rationale for Prenatal Disability Screening" by Wasserman & Asch</p>	Short Paper (due 11/3 by end of the day)
November 6 th	<i>No class</i>		
November 13 th	Testing Children and Newborns	ASHG Position Statement: "Ethical, Legal, and Psychosocial Implications of Genetic Testing in Children and Adolescents"	Discussion post (due by end of day 11/12)
November 20 th	Direct-to-Consumer Testing	"Is That a Threat or a Promise?: Direct-to-Consumer Marketing of Genetic Testing" by Hercher	Discussion post (due by end of day 11/19)
November 27 th	<i>No class</i>		
December 4 th	Review (in class)		
December 11 th	<i>Final exam during class time</i>		

8.3 Tentative Media Schedule

None

9.0 Instructional Staff

Laura Guidry-Grimes, PhD

Course Director

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College of Medicine, Department of Medical Humanities and Bioethics
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Noelle Danylchuk, MS, CGC**Instructor**

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10.0 CHP Copyright Policy & Disability Policy

Copyright Policy - The materials used in this course may include copyright protected materials provided for the personal educational use of the enrolled students and may not be further redistributed.

Intellectual Property Policy - Lecture, lab and other presentations are the intellectual property of the faculty and faculty must give their written permission for their lecture, lab, and other presentations to be recorded. Recorded lectures/labs/presentations may only be posted on websites or other locations approved by the College of Health Professions and are provided for the personal educational use of students enrolled in the course. Students are prohibited from providing or distributing any course materials in any manner – print, electronic, or any other media – or providing links to any course materials to anyone outside of their UAMS classes. Failure to abide by this policy may result in disciplinary action including dismissal. Failure to abide by this policy may constitute a copyright infringement which may have the following legal consequences:

Summary of Civil and Criminal Penalties for Violating Federal Copyright Laws

Copyright infringement is the act of exercising, without permission or legal authority, one or more of the exclusive rights granted to the copyright owner under section 106 of the Copyright Act (Title 17 of the United States Code). These rights include the right to

reproduce or distribute a copyrighted work. In the file-sharing context, downloading or uploading substantial parts of a copyrighted work without authority constitutes an infringement. Penalties for copyright infringement include civil and criminal penalties. In general, anyone found liable for civil copyright infringement may be ordered to pay either actual damages or "statutory" damages affixed at not less than \$750 and not more than \$30,000 per work infringed. For "willful" infringement, a court may award up to \$150,000 per work infringed. A court can, in its discretion, also assess costs and attorneys' fees. For details, see Title 17, United States Code, Sections 504, 505. Willful copyright infringement can also result in criminal penalties, including imprisonment of up to five years and fines of up to \$250,000 per offense. For more information, see the web site of the U.S. Copyright Office at www.copyright.gov, and especially their FAQs at www.copyright.gov/help/faq

Title IX - The University of Arkansas for Medical Sciences (UAMS) does not discriminate on the basis of sex, gender, or sexual orientation in its education programs or activities. Title IX of the Education Amendments of 1972, and certain other federal and state laws, prohibit discrimination on the basis of sex in all education programs and activities operated by UAMS (both on and off campus). Title IX protects all people regardless of their gender or gender identity from sex discrimination, which includes sexual harassment and sexual violence.

The UAMS Title IX Coordinator can be contacted at (501) 526-5641. She is available to explain and discuss: your right to file a criminal complaint (sexual assault and violence); the university's complaint process, including the investigation process; how confidentiality is handled; available resources (both on and off campus); and other related matters. **You may also contact the UAMS Police Department, 501-686-7777 (non-emergency) or 911 (emergency). If you are in the midst of an emergency, please call the police immediately by dialing 9-1-1.**

The United States Department of Education's Office of Civil Rights ("OCR") is responsible for enforcing Title IX, as well as other federal civil rights laws that prohibit discrimination in programs or activities that receive federal financial aid. Inquiries and complaints may also be directed to OCR at 1-800-421-3481 or ocr@ed.gov

DISABILITY SUPPORT – UAMS is committed to providing equal access to learning opportunities to students with disabilities. To ensure access to any class or program, please contact the ADA Coordinator to engage in a confidential conversation about the process for requesting accommodations in the classroom and clinical settings. Accommodations are not applied retroactively. Students are encouraged to register with the ADA Coordinator's office as soon as they begin their program or as soon as the student recognizes their need for an adjustment.

UAMS encourages students to access all resources available through the ADA Office for consistent support and access to their programs. More information can be found online at <http://students.uams.edu/ada-disability-services/> or by contacting the disability services office at (501) 526-5641.

11.0 Scholastic Misconduct and Plagiarism

Scholastic misconduct applies to circumstances and events related to the student's education program, including scholastic dishonesty and professional conduct or judgment. This includes, but is not limited to, plagiarism, giving or receiving any form of aid on quizzes or examinations that is not expressly permitted by the instructor, or falsification of documents, experimental results, or research data. Sanction(s) may include, but are not limited to, a failing grade on the test/assignment, failing grade for the course, probation, suspension or dismissal from the college. Policies and procedures for scholastic dishonesty or other non-academic disciplinary matters are addressed in procedures and regulations in the Student Conduct and Discipline Policy located in the CHP Catalog.

The College of Health Professions subscribes to a Web-based plagiarism detection and prevention system that is used by colleges and universities nationwide. The system works by scanning the submitted document and matching the document against databases of texts, journals, and Web and other electronic sources including websites that sell or distribute

pre-written essays and/or term papers. As your course instructor, I am informing you via this syllabus that I reserve the right, at my discretion, to use this plagiarism detection system for this course by submitting students' written work to the system for the purpose of determining if a document has been plagiarized.

Note: All work submitted for this course is required to be original work developed for class assignments and should not have been submitted for assignments made as part of previous and/or concurrent courses without the instructors' prior knowledge and approval; to do otherwise constitutes academic dishonesty and will be addressed as such in this course.

12.0 Patient Privacy and Confidentiality

UAMS is committed to protecting the privacy of our patients' information. While privacy and confidentiality have always been a priority for health care providers, it has heightened importance in this era of electronic information due to the increased speed of information flow and the risks associated with protecting this information.

The standards for protecting patient health information are described in the federal law known as the Health Insurance Portability and Accountability Act (HIPAA). HIPAA limits access to medical records to authorized individuals and for specific purposes. It is not possible to summarize HIPAA here; however, you will have received HIPAA training prior to being granted access to patient information. Additional information and training on HIPAA, including UAMS HIPAA policies, are available on the HIPAA Office webpage at <http://hipaa.uams.edu/>

Please keep in mind that there are sanctions for inappropriate access to patient records. These include criminal penalties of up to one (1) year imprisonment and a \$50,000 fine; as well as, disciplinary action up to and including dismissal from your program.

If you have any questions pertaining to HIPAA, you may direct them to the UAMS HIPAA office at 501-603-1379.