

ENGL 105i – Unit 3
Writing in the Health Humanities: Illness Narrative

Genre	Audience	Role	Purpose	Rhetorical Situation
Illness narrative	Healthcare workers and other people experiencing a similar illness or condition as the one described in your narrative	Health Humanities scholar	To inform healthcare workers about a person’s lived experience of disease, illness, or some other medical condition so they are better equipped to treat their patients	You are a scholar in the Health Humanities interested in using Narrative Medicine to communicate the lived experiences of illness, disease, or some other medical condition to healthcare workers in an effort to improve healthcare practices.

Overview

For our third unit, we will explore how notions of health and medicine are harnessed and explored artistically and philosophically. We will also examine how the tactics and methods employed within the Humanities (close reading; original interpretations; embracing subjectivity, uncertainty, and contradiction) can be employed to create a more humane and effective form of health care known as Narrative Medicine, a specific subset of the Health Humanities.

Rita Charon is often cited as coining the term “narrative medicine.” She defines the term as “medicine practiced with these narrative skills of recognizing, absorbing, interpreting, and being moved by the stories of illness. As a new frame for health care, narrative medicine offers the hope that our health care system, now broken in many ways, can become more effective than it has been in treating disease by recognizing and respecting those afflicted with it and in nourishing those who care for the sick.”¹

Meanwhile, Arthur Frank, another significant scholar of the Health Humanities, explains the vital relationship between illness and stories: “Becoming seriously ill is a call for stories in at least two senses.... Stories have to repair the damage that illness has done to the ill person’s sense of where she is in life, and where she may be going.... The second and complementary call for stories is literal and immediate: the phone rings and people want to know what is happening to the ill person.... Whether ill people want to tell stories or not, illness calls for stories.”²

Doctors and other health care workers should fill this need for stories by engaging with illness narratives. The scholar Arthur Kleinman argues that “the study of the experience of illness has something fundamental to teach each of us about the human condition, with its universal suffering

¹ Rita Charon, *Narrative Medicine: Honoring the Stories of Illness*. Oxford UP, 2006, p. 4.

² Arthur Frank, *The Wounded Storyteller: Body, Illness, and Ethics*, 2nd ed. Chicago: U of Chicago P, 2013, pp. 53-54.

and death.... Indeed, the interpretation of narratives of illness experience, I will argue, is a core task in the work of doctoring, although the skill has atrophied in biomedical training.”³

With this assignment, you have the opportunity to put these ideas into action. You will conduct primary research through the role of interviewer and active listener as another person tells you their story. Absorbing what they say, and drawing on a variety of resources, you will in turn become a storyteller: interpreting and sharing their experiences by writing an illness narrative of at least 1,200 words. This will involve interviewing someone with a disease, illness, injury, or other health condition and then writing a narrative of their lived experience, incorporating secondary research and your own reflections on what such an experience reveals about larger concepts related to health and medicine.

Note that for all of our work in Unit 3, we will be using the Modern Language Association (MLA) 8th edition citation format, the citation format most commonly used by scholars in the Humanities. Your primary source of information on MLA 8th edition citation format should be the UNC Libraries. See the following pages:

- UNC Libraries: “[Why We Cite](#)”; [MLA 8th ed.](#): “[Sample Works Cited Page](#),” “[In-Text Citations](#),” “[Print Sources](#),” “[Online Sources](#)”

Feeder 3.1 is a Preliminary Analysis Worksheet in which you select the specific person you will interview for your illness narrative, consider what you know about that person, and plan potential interview questions. You will also identify potential secondary sources to provide further context and insight on the topics discussed in your illness narrative. Feeder 3.1 is worth 5% of your final course grade.

- Tues. Nov. 2: Choose UP3 Topics in class (Sakai forum post)
- Wed. Nov. 3: Feeder 3.1 Rough Draft due by 11:59pm (Sakai forum post)
- Mon. Nov. 8: Feeder 3.1 Final Draft due for a grade by 11:59pm (Sakai>Assignments)

Feeder 3.2 consists of your Interview Notes, notes from your primary research. This is not a full transcript of your interview but the beginning of your attempt to consolidate what you’ve learned from your interview into the form of a written narrative. Feeder 3.2 is worth 5% of your final course grade.

- Mon. Nov. 15: Feeder 3.2 Rough Draft due by 11:59pm (Sakai forum post)
- Wed. Nov. 17: Feeder 3.2 Final Draft due for a grade by 11:59pm (Sakai>Assignments)

Unit Project 3 will be an Illness Narrative in which you synthesize your secondary research with your primary research to create an ethical, respectful, insightful narrative that explores the story of this person’s experience living with a specific illness or medical condition. Unit Project 3 is worth 15% of your final course grade.

- Mon. Nov. 22: UP3 Rough Draft due by 11:59pm (Sakai forum post)
- Mon. Nov. 29: UP3 Final Draft due for a grade by 11:59pm (post to the course website)

For more detailed instructions for each feeder and your unit project, including grading rubrics, etc., see below. Always remember to refer to the specific instructions and guidelines listed in this document, including grading rubrics, as well as any samples or models we discuss in class.

³ Arthur Kleinman, *The Illness Narratives: Suffering, Healing & the Human Condition*. New York: Basic Books, 1988, p. xiii.

Feeder 3.1: Preliminary Analysis Worksheet

What is an illness narrative? How is it different from a case study?

Healthcare work and a purely biomedical approach to treatment can sometimes have a detrimental impact on a patient's sense of personhood and identity. Dan Gottlieb explains that "When we're admitted to a hospital or even visiting a doctor, the forms ask for 'Patient Name.' We stop being people and start being patients.... Our identity as people and the world we once knew both are relinquished; we become their patients and live in their hospital."⁴

In contrast, an illness narrative seeks to prioritize the person living with a condition rather than the condition itself. First and foremost, an illness narrative tells the **story of a person**. It is the opportunity to go beyond the "medical story" into the story of a particular individual who was (or is) ill, injured, experiencing a health condition, or disabled. It addresses questions such as, "Who has helped you get through this period in your life?" and "How has this condition changed the way you live?" (not just the standard clinical questions like, "Where does it hurt?" or "What medications are you taking?"). Illness narratives, in fact, often reflect on the medical treatment an individual received/receives, weaving it into the larger experience. An illness narrative provides the opportunity to tell a more complex, personal, ambiguous, interconnected, and challenging story than what appears on a medical chart.

An illness narrative can be a form of **autobiography**: writing that gives expression to the experience of being sick, disabled, or chronically ill, from the perspective of the sick person. Autobiographical illness narratives are generally written in the first person.

An illness narrative can also be a form of **biography**: written by someone who is not ill but who has listened intently and with care to someone else describe their experience. This sort of illness narrative is usually written in the third person and is most likely what you will write.

Importantly, an illness narrative includes **analysis** as well as **description**: it reflects on the person's experience of illness and comments on its significance. It addresses these sorts of questions: What does this person's story suggest about medical care today? About the ways in which illness affects a person's beliefs, sense of self, ability to do one's job, relations with others, feelings of safety or vulnerability, attitudes toward the medical profession, social standing, one's own identity, etc.? About the economics of healthcare? **Consider also** whether this person's experience of illness echoes any other ideas or concepts such as (but not limited to):

- resilience, dignity, suffering, empathy, care
- the significance of gender, race, class, sexual orientation and expression, etc. in illness and treatment
- how modern medicine conceptualizes disease or what it means to be "healthy" or a "person"
- physician authority or fallibility
- medical personnel's tact, attentiveness, or shortcomings
- techniques of diagnosis
- social stigma
- the role of culture

⁴ Dan Gottlieb, "Patients Must Insist that Doctors see the Face behind the Ailment," *The Philadelphia Enquirer*, July 4, 1994, quoted in Frank, *The Wounded Storyteller*, p. 10.

- the economics or politics of health
- death, dying, and mortality

How do I get started on my illness narrative?

First off, keep in mind that you don't have to write about a devastating experience of illness. Richly telling the story of a grandparent's experience with aging, with all that it includes (physical and medical, for sure, but also emotional and spiritual) could be a highly productive response to the assignment. Experiences such as childbirth, living with diabetes, weathering an injury, or seeking help for depression may not have the immediate "drama" of being diagnosed with a rare disease but may be rich terrain to explore. (Virginia Woolf once wrote about a toothache! It's a great essay, called "[On Being Ill.](#)")

i. Whom to write about

The important thing here is to talk to people, to tell them about the project, and seek suggestions for who to interview. Sometimes, friends or family members nominate themselves! You may decide to write about the experience of someone you know well, someone you know a little bit, or someone you don't know at all. This last category may seem odd, but you might find interesting people to interview from recommendations of others or even from sources such as illness blogs. People who write publicly about their experience are often willing to be interviewed. As with all such encounters, the safety of both parties is crucial. Please consult with me for suggestions about how to meet up in a safe and comfortable context. Be sure to maintain social distancing, wear a mask, etc. Right now, it might be best to conduct your interview remotely through something like Zoom, etc.

ii. Interview questions

Arthur Kleinman developed the following questions as a way to understand how someone from another culture understands his or her illness.⁵ (Note: The appropriate verb tense for these questions will depend on whether the individual's medical condition is in the past or ongoing.)

- (1) What do you call the problem?
- (2) What do you think has caused the problem?
- (3) Why do you think it started when it did?
- (4) What do you think the sickness does? How does it work?
- (5) How severe is the sickness? Will it have a short or long course?
- (6) What kind of treatment do you think you should receive? What are the most important results you hope to receive from this treatment?
- (7) What are the chief problems the sickness has caused?
- (8) What do you fear most about the illness?

While Kleinman's questions were designed to bridge a cultural divide, they do point in a good direction by focusing on the individual's perceptions rather than the views of medical personnel. These are a starting point for your own narrative, not a definitive list of questions to ask.

For an excellent, comprehensive list of questions—far too many to actually use, in fact—please [consult this guide](#). This document is also posted on Sakai at Resources>Unit 3>Model Illness Narratives>"McGill – Illness Narrative Interview."

⁵ Kleinman's questions appeared in Anne Fadiman's book, *The Spirit Catches You and You Fall Down*.

The first step of your project is to determine who you wish to interview. In class on Tues. Nov. 2, we will discuss the values, priorities, and strategies for writers in the Humanities, the Health Humanities, and Narrative Medicine. You will also be given the opportunity to discuss potential interviewees for Unit Project 3 with your group members. This means that, prior to that class session, you should have read this assignment prompt and begun considering potential interviewees.

To actually get started on your illness narrative, you will complete your first feeder of the unit, a “Preliminary Analysis Worksheet” (Sakai>Resources>Unit 3). This worksheet is designed to help you choose the main subject of your narrative, the person you will interview. In completing this worksheet, you will also analyze what you know about this person, conduct some secondary research, and plan your list of potential interview questions. You should also develop a tentative research question to drive all of your work moving forward: what do you hope to learn from this person?

A rough draft of your worksheet is due Wed. Nov. 3 by 11:59pm via the appropriate Sakai forum. This rough draft should be attached to your post as its own document. We will workshop this in class on Thurs. Nov. 4. The file name for this document should be “[Your last name]_3.1 Rough Draft.” This draft does not have to be entirely complete, but it should be as close to complete as possible for you to maximize the benefits from the workshop in class.

Based on your workshop experience, revise and complete your Feeder 3.1 into a separate, final draft. This final draft of Feeder 3.1 is due for a grade on Mon. Nov. 8 by 11:59pm via the “Assignments” tab on Sakai. The file name for this document should be “[Your last name]_3.1 Final Draft.

Successful worksheets will:

- Display considerable investment in the revision process.
- Contain questions that are all answered in a complete and accurate manner.
- Reference useful secondary sources to provide context or insight on the selected topic, accompanied by accurate and complete bibliographic citations in MLA 8th edition format.
- Include planned potential interview questions.
- Exhibit the student’s careful critical engagement with the selected interview subject, the related illness narrative, and other aspects of the subject’s identity.

Grading Rubric for Feeder 3.1: Preliminary Analysis Worksheet

The final grade for Feeder 3.1 will be worth 5% of the student’s final course grade.

	10	7	4	1
Question 1	Answered completely, accurately, and appropriately.	Some information is lacking or inaccurate.	The response is cursory at best and does not provide enough information for the reader to understand.	Little to no response to the question.
Question 2	Answered completely,	Some information is lacking or inaccurate.	The response is cursory at best and does not provide	Little to no response to the question.

	accurately, and appropriately.		enough information for the reader to understand.	
Question 3	Answered completely, accurately, and appropriately.	Some information is lacking or inaccurate.	The response is cursory at best and does not provide enough information for the reader to understand.	Little to no response to the question.
Question 4 (worth double: 20, 14, 8, or 2 points)	Answered completely, accurately, and appropriately.	Some information is lacking or inaccurate.	The response is cursory at best and does not provide enough information for the reader to understand.	Little to no response to the question.
Question 5 (worth double: 20, 14, 8, or 2 points)	Answered completely, accurately, and appropriately.	Some information is lacking or inaccurate.	The response is cursory at best and does not provide enough information for the reader to understand.	Little to no response to the question.
Style	Worksheet features varied and sophisticated sentence structure and diction. Style changes when appropriate based on the specific questions.	Worksheet uses some repetitive diction, overly simplistic language or sentence structures but mostly maintains a professional and objective tone.	Worksheet occasionally lapses into overly casual, colloquial discourse or subjective claims. Writing appears erratic, and some sentences are hard to follow.	Major lapses into casual discourse or little attempt to maintain objectivity. Diction is highly repetitive, and syntax is confusing or highly inappropriate.
Citations	A coherent citation system (MLA 8 th edition format) is used consistently throughout; Works Cited list is complete and formatted accurately.	A citation system is systematically used with some lapses in providing required bibliographical information; Works Cited list does not include all sources cited in body of text.	It is very difficult to tell if a single citation system has been adopted throughout. Citations are erratic, and/or Works Cited list is incomplete.	No effort at citing sources accurately and consistently is made.
Grammar	Worksheet is free from typographical errors as well as spelling and grammar mistakes.	A few surface errors but none so consistent that they obscure the student-author's meaning.	Repeated surface errors.	No sign of editing or revision.
Total: /100				

Feeder 3.2: Interview Notes

Revisit the secondary sources you listed in Feeder 3.1. Skim these sources to find useful information that will inform your interview and, eventually, the narrative you write. Use my feedback on Feeder 3.1 as well to guide you as you revise and finalize your interview questions and prepare for your interview overall. Once you are ready, conduct your interview, taking careful notes. But first, be sure to read through this section of the assignment prompt for more guidance. It's most likely that you will have to conduct your interview (and compose your polished notes) during the weekend of Nov. 12.

What goes into writing an illness narrative?

Arthur Frank explains: "What makes an illness story good is the act of witness that says, implicitly or explicitly, 'I will tell you not what you want to hear but what I know to be true because I have lived it.'... In telling this story truthfully, the ill person rises to the occasion" (Frank 63). An illness narrative gives expression to the lived experience of illness.

To write an illness narrative about another person, you will need to: 1) talk with a person about their experiences in life, health, and health care, 2) tell that person's story, and 3) reflect on what the story of illness helps to illuminate. The **voice** and **perspective** of the ill person is the starting point. An illness narrative may include symptoms, diagnoses, biomedical treatments, disease prognoses—but **only insofar as they relate to the experience of the sick person**. Your interview is a form of primary research; illness narratives often integrate secondary research to contextualize or inform points made. However, the emphasis should be on the narrative of the person you interview. (Note: This narrative is NOT just a transcript of your interview. The information from your interview provides the starting point, the data with which you have to work as you construct a narrative reflecting on this person's lived experience with a medical condition. Your secondary sources will provide useful background information, context, and other insights to further illuminate the narrative, but the focus should be on the narrative itself.)

Your unit project will seek to convey honestly and clearly the **details** of an individual's experience of illness and also reflect on its **significance**. A key question to keep in mind for the analytical part of the paper: what emerges when the story of a health condition (e.g. the "heart patient in Room 6") centers on the lived experience, voice, and context of the ill person, rather than giving just the biomedical version of a disease/injury/disability/source of suffering?

An illness narrative has many of the same attributes as other successful forms of writing:

- it has a beginning, middle, and end (though these do not need to be chronological)
- it has structure: an organizing principle that connects the beginning, middle, and end (examples of different ways of structuring your narrative are provided below)
- it includes reflection and analysis, along with description and dialogue
- it includes concrete, significant details that appeal to the five senses and avoids clichés and abstraction
- it includes active verbs, well-chosen words, metaphors, and figures of speech

iii. Important Notes about Conducting an Interview

Most important: plan ahead. You'll of course want to set up the interview in advance and explain to your interviewee what to expect. Ideally, you will schedule a follow-up interview, as well (or perhaps several). While most of you will be interviewing people you know, you'll want to make clear your

own position and limitations: you are an undergraduate student, conducting such an interview (likely) for the first time, you're working in the context of a composition class with a focus on health and medicine, you may have some knowledge of the illness from conducting background research or other sources but are not any sort of expert on it, and so on. Try to arrange for enough time to meet (at least an hour) and establish an end point in advance; it can be tiring to talk at length, especially about a health condition.

The privacy and well-being of your interview subject/s (and anyone they mention) is paramount:

- The topic of your discussion could be upsetting or triggering for you and/or your interviewee; be sensitive on both fronts. Maintain self-care, but also be responsible and sensitive in how you structure and phrase your interview.
- Before you begin your interview, remind your interviewee of the context: you are an undergraduate student, not an expert. You should make sure your interviewee understands that this material will be posted to our course website; the level of visibility of your post will be dictated not only by your desire but also by theirs. If they want this post private (only visible to your instructor), you must abide by that choice. If they are willing for it to be accessible to your classmates, you must make sure you password-protect your post. If they are willing to share it with all members of the UNC community, you should require website visitors to log in using their ONYEN. It seems highly unlikely that they will grant consent for your post to be public. If they wish to be anonymous or pseudonymous, you must respect that decision. Your safest choice is to disguise all people referenced in the narrative.
- You should explicitly find out if they wish to share their information publicly, pseudonymously, or anonymously. However, even if your interviewee wishes to share their information publicly, their interview content might include information regarding other people; even if your interviewee provides consent to share their individual info publicly, they cannot provide consent for the information of others to be shared publicly. Your most ethical choice is to refer to all individuals in your interview narrative via pseudonyms. You **MUST** respect the wishes of anyone you interview regarding their right to privacy. You can choose to make your final project more private than they wish, but you cannot make it more public than they wish. You should inform your interviewee how they will be represented and how it will be shared.
- Be mindful that your drafts of Feeder 3.2 and your Unit Project will be visible to all of your classmates, so you need to protect identities even in your early drafts.
- Your notes should begin with a statement regarding the privacy of your interview subject(s) such as: **“The interview subject(s) of the following narrative have granted permission for this content to be shared as long as their identities are protected; all individuals referenced have been assigned pseudonyms.”**

Make sure to have a comfortable and safe setting for your interview. You may wish to record the interview, though you'll need to ask if that is ok with the person you're speaking to; in any case, do make sure to take notes (and to alert the person that you will be doing so) as technology is notoriously unreliable. Again, it's permissible to conduct your interview remotely if need be. When conducting your interview, refer to the “Quick Guide to Interviews and Observations” (Sakai>Resources>Unit 2).

The feeder you submit should not be a transcript of your interview; use your transcript and rough notes to begin constructing the narrative of this person’s lived experiences of illness. The notes you submit should be polished, logically organized, and clearly written and should sum up the major components of your primary research (your interview). You do not have to include every aspect of your interview, but your notes, written like a miniature essay or story, should include (or at least touch on) any significant portions of this person’s narrative. Include at the end of your notes a Works Cited list; the only source listed should be a full, bibliographic citation for your interview. See the MLA Works Cited Sample on Sakai at Resources>Unit 3 for how to cite an interview, although it’s most likely that your citation will look like one of the following:

- Smith, John [pseudonym]. Interview. Conducted by Paul Blom, 21 Oct. 2021.
- Smith, John [pseudonym]. Personal communication with author. 21 Oct. 2021.
- Smith, John [pseudonym]. Teleconference interview with the author, 21. Oct. 2021
- Smith, John [pseudonym]. Telephone interview with the author, 21. Oct. 2021.

Remember: You’ll have submitted your final draft of Feeder 3.1 on Mon. Nov. 8. I will work hard to get you your feedback in a matter of days so you can adjust your interview plan as needed. Your best bet is to schedule your interview for the weekend of Nov. 12.

A rough draft of your interview notes is due Mon. Nov. 15 by 11:59pm via the appropriate Sakai forum. This rough draft should be attached to your post as its own document. We will workshop this in class on Tues. Nov. 16. The file name for this document should be “[Your last name]_3.2 Rough Draft.” This draft does not have to be entirely complete, but it should be as close to complete as possible for you to maximize the benefits from the workshop in class.

Based on your workshop experience, revise and complete your Feeder 3.2 into a separate, final draft. This final draft of Feeder 3.2 is due for a grade on Wed. Nov. 17 by 11:59pm via the “Assignments” tab on Sakai. The file name for this document should be “[Your last name]_3.2 Final Draft.

Successful interview notes will be clearly written and logically organized in the form of a narrative that begins to tell the story of this person’s lived experience with illness. It should feature careful diction, imagery, reflection, and, when appropriate, direct quotations from your interviewee. These notes will lay the foundation for what will eventually become a complete illness narrative.

Grading Rubric for Feeder 3.2: Interview Notes

The final grade for Feeder 3.2 will be worth 5% of the student’s final course grade.

	10	7	4	1
Interviewee (worth double: 20, 14, 8, or 2 points)	Writer clearly offers a holistic portrait of the interview subject that goes beyond their biomedical diagnosis; interviewee is presented in their	Writer attempts to present aspects of their interviewee’s individual complexity but still relies too much on biomedical diagnosis and data.	Writer provides virtually no sense of the interviewee’s individual complexity; the interview subject is presented almost exclusively in the context of their illness.	Writer relies exclusively on biomedical information about the illness discussed and provides almost no information about their interview

	individual complexity and is not eclipsed by their illness.			subject from either a biomedical or holistic approach.
Integration of Interviewee's Voice (worth double: 20, 14, 8, or 2 points)	Writer adeptly uses a combination of direct quotes, summaries, or paraphrases to integrate the contents of their interview subject's narrative into their overall paper.	Writer uses some direct quotes and summaries, but the integration of the interviewee's voice is still insufficient.	Writer only refers to their subject's narrative in very vague or unspecific terms.	Writer makes no appreciable effort to integrate their interview subject's voice into their paper.
Analysis	Writer identifies specific patterns, categories, or relationships between the data.	Writer identifies patterns, categories, or relationships, but the connections drawn are sometimes unclear or vague.	Writer provides analysis that is mostly cursory, over-generalized, or not explored in depth.	Writer makes no attempt to identify such patterns or relationships between data.
Organization	The narrative is organized with a logical and explicit pattern appropriate to this genre.	The narrative is mostly well-organized, but some paragraphs seem out of order or repetitive.	The narrative is very confusingly organized and does not reflect an overall organizational pattern.	The narrative is organized so confusingly that it impedes the author's purpose.
Style	The narrative features varied and sophisticated sentence structure and diction as well as vivid details and imagery, often prioritizing showing rather than telling.	The narrative uses some repetitive diction, simplistic language or sentence structures but mostly maintains an appropriate tone.	The narrative occasionally lapses into casual, colloquial discourse or subjective claims at inappropriate moments. Writing appears erratic, and some sentences are hard to follow. Writer displays an overreliance on telling rather than showing.	Major lapses into casual discourse or little attempt to maintain an appropriate tone. Diction is highly repetitive, and syntax is confusing. Complete lack of imagery or detail.
Citations	A coherent citation system (MLA 8 th edition format) is used	A citation system is systematically used with some lapses in providing required	It is very difficult to tell if a single citation system has been adopted throughout. Citations are	No effort at citing sources accurately and consistently is made.

	consistently throughout; Works Cited list is complete and formatted accurately.	bibliographical information; Works Cited list does not include all sources cited in body of text.	erratic, and/or Works Cited list is incomplete.	
Grammar	The narrative is free from typographical errors as well as spelling and grammar mistakes.	A few surface errors but none so consistent that they obscure the writer's meaning.	Repeated surface errors.	No sign of editing or revision.
Total: /90				

Unit Project 3: Illness Narrative (1,200 to 1,500 words)

Revisit your secondary sources and read them more carefully. You may also find it useful to conduct further secondary research and/or to conduct a brief follow-up interview with your interview subject. Use the information gained from your interview and the information gained from your secondary research to synthesize this material into an ethical, respectful, insightful narrative of this person's illness.

Literary scholars, theorists, and philosophers use the skills of close-reading, analysis, speculation, and empathy to interpret the texts, cultures, and worlds around them. You will use these same kinds of skills to closely read and interpret your interview subject: the words they use, the events of their lives, their experiences with illness, and how they form meaning about their lives and their illness.

How do I structure my illness narrative?

Once you gather your material together, you will need to decide how to present it. Where to begin? How to organize the middle of the story? How to wrap it up, without being too "tidy"? Illness narratives can take many forms. Start with a central research question that introduces and frames your narrative, something as seemingly simple as "What is it like to live with chronic pain?" or "How does dementia affect and transform someone's identity?" Your narrative should explore the answers to that question. Although you should approach your interview with a tentative research question in mind, one that has helped to shape the questions you will ask, you should (as always) be ready to adjust that research question based on the information you gather.

There are many different ways to structure or organize your narrative. Arthur Kleinman's book *The Illness Narratives* provides helpful examples such as the illness narrative of Howie Harris in chapter 3 of his book, beginning on page 60 (Sakai>Resources>Unit 3>Readings on Illness Narratives). See also the model illness narratives I've provided, although you should note those models are much longer than I expect you to write (Sakai>Resources>Unit 3>Model Illness Narratives).

Remember, you're helping to tell someone's story, sometimes paraphrasing or summarizing and sometimes using their direct quotes when appropriate (as full sentences or even just as small phrases

or diction worth discussing). But you should also analyze the content of the interview (their language and the events themselves) and include a bit of commentary or reflection, either interwoven into the narrative or written as its own section. How do these experiences relate to larger concepts related to health, medicine, healthcare, disease, etc.? Your conclusion should wrap things up and gesture towards larger implications: what does this one narrative reveal about larger concepts? What can we learn or take away from this one narrative beyond this one specific story?

Note: After your title but before the content of your narrative, provide an opening disclaimer regarding the permission the interviewee has granted regarding the visibility of the post. Here's a model to use. You'll have to adjust the material included in brackets depending on your interviewee's wishes:

The individual[s] interviewed for this illness narrative [has/have] given express permission for this narrative to be published on our course website [publicly/accessible only to the UNC community/protected with a password/private], [with their full name attached/with their name (and any other identifying details) replaced, changed, or removed]. These individuals understand that they can alter these permissions at any time.

Timeline for Unit Project:

A rough draft of your illness narrative is due Mon. Nov. 22 by 11:59pm via the appropriate Sakai forum for us to workshop in class on Tues. Nov. 23. The file name for this document should be “[Your last name]_UP3 Rough Draft.” This draft does not have to be entirely complete, but it should be as close to complete as possible for you to maximize the benefits from the workshop in class.

Based on your workshop experience, revise and complete your illness narrative into a separate, final draft. This final draft of your Unit Project is due for a grade on Mon. Nov. 29 by 11:59pm via the course website. This means you will need to take your final draft Word document and copy and paste it as a post on our course website. This will take time, but your completed draft must be published online by 11:59pm, so you should start this process early. Your submissions are time-stamped, and once the deadline has passed, if you go back and revise, your illness narrative will be considered late.

Technical Info:

For technical information on how to access and log into the course website or how to compose, edit, and publish a post, etc., see the document “Instructions for Posting to the Course Website” on Sakai at Resources>Course Website Resources.

- Do not alter any settings for the blog or any other webpage or the site in general.
- Remember to set a Featured Image for your post and cite it appropriately. (The citation for your Featured Image should always be the final element of your post, below and separate from your bibliography.)
 - See “How to Cite Images, Visuals, Data Visualizations, etc.” (Sakai>Resources>Helpful Handouts and Resources) for how you should cite your Featured Image and any other images, data visualizations, etc. you include in your post.

- Your post should include an MLA 8th edition format Works Cited for your interview and all secondary sources. If those citations contain urls, activate those urls as hyperlinks for our website visitors.
- Add tags for your post.
- Categorize your post as “Health Humanities: Illness Narratives.”
- Remember to hit “Publish” near the top-right corner when you’re done. After you publish/update your post, I suggest you view your post like any other online visitor to double-check one final time, just in case you need to go back and edit changes. Log out from our site and return to your post; make sure your content appears correctly.
- Your post must be complete and accessible by the assignment deadline.
- If you only want to share your post with members of the UNC community, require ONYEN authentication to access your post; if you only want to share your post with members of our classroom community, password-protect your post (using the class password); if you only want to share your post with me, publish your post as “Private.”

Successful illness narratives will have:

- An engaging and descriptive title
- A disclaimer about the patient’s permission
- A research question that introduces and frames the narrative
- Rich imagery
- A distinctive and consistent narrative voice suited to your narrative’s subject
- Characters developed as fully as possible through details or dialogue
- A vivid, compelling setting
- A clear story arranged in a meaningful (probably, but not necessarily, chronological) order
- Thoughtful analysis and reflection
- Useful outside sources to provide insight on the narrative
- A conclusion that suggests larger implications of this narrative and answers your research question based on the cumulative content of the illness narrative
- A complete Works Cited list citing the bibliographic citations for the interview and all secondary sources included in the narrative.

The writing should “show” with concrete, significant details instead of simply “telling.” You should include perceptive analysis and insight into this particular experience of illness/health condition, and you should conclude by gesturing towards the larger implications of this one narrative.

Grading Rubric for Unit Project 3: Illness Narrative

The final grade for UP3 will be worth 15% of the student’s final course grade.

	10	7	4	1
Interviewee	Writer clearly offers a holistic portrait of the interview subject that goes beyond	Writer attempts to present aspects of their interviewee’s individual complexity but still	Writer provides virtually no sense of the interviewee’s individual complexity; the interview subject is presented	Writer relies exclusively on biomedical information about the illness

	their biomedical diagnosis; interviewee is presented in their individual complexity and is not eclipsed by their illness.	relies too much on biomedical diagnosis and data.	almost exclusively in the context of their illness.	discussed and provides almost no information about their interview subject from either a biomedical or holistic approach.
Integration of Interviewee's Voice	Writer adeptly uses a combination of direct quotes, summaries, or paraphrases to integrate the contents of their interview subject's narrative into their overall paper.	Writer uses some direct quotes and summaries, but the integration of the interviewee's voice is still insufficient.	Writer only refers to their subject's narrative in very vague or unspecific terms.	Writer makes no appreciable effort to integrate their interview subject's voice into their paper.
Research Inquiry	Writer articulates a clear and specific research question regarding their subject matter, a research question that will provide the purpose of writing this narrative.	Writer articulates a research question but does so in confusing or unclear language.	Writer states vague or generalized goals for the narrative or presents a research question that is underdeveloped and could be easily and succinctly answered by another genre.	Writer offers no explicit research question to guide their narrative or provides one that is totally unintelligible.
Conclusions	Writer explicitly answers their research question by using their observations and analysis to draw an overall conclusion that also gestures towards larger implications.	Writer makes some effort to answer their research question and articulate the wider implications of their narrative.	Writer provides very cursory concluding statements that do not appear explicitly related to their research question.	No conclusions or incomprehensible conclusions are offered.
Background Research	Secondary sources are	Secondary sources are mostly	Summaries and paraphrases are	Sources are pulled in as direct quotes,

	excellently paraphrased and summarized and are incorporated into the writing using correct citations. This outside information successfully contextualizes or illuminates aspects of the narrative.	integrated well into the narrative with a few lapses or awkward inclusions or citations; or the narrative displays an overreliance on outside information.	confusing, awkward, and do not flow well with the rest of the paragraph.	and almost no effort is made to paraphrase or summarize them. The inclusion of this material is not contextualized or does not clearly apply to the content being discussed. Significant problems with citations are present.
Analysis	Writer identifies specific patterns, categories, or relationships between the data.	Writer identifies patterns, categories, or relationships, but the connections drawn are sometimes unclear or vague.	Writer provides analysis that is mostly cursory, over-generalized, or not explored in depth.	Writer makes no attempt to identify such patterns or relationships between data.
Health Humanities	Writer clearly connects illness narrative to at least one core concept related to Health Humanities, personhood, etc.; this connection is fully fleshed out and explained.	Writer connects their narrative to a class concept but does so in an underdeveloped or confusing manner.	Writer makes only superficial connections to class concepts.	Writer makes almost no attempt to connect their narrative to health humanities concepts.
Organization	The narrative is organized with a logical and explicit pattern appropriate to this genre.	The narrative is mostly well-organized, but some paragraphs seem out of order or repetitive.	The narrative is very confusingly organized and does not reflect an overall organizational pattern.	The narrative is organized so confusingly that it impedes the author's purpose.
Style	The narrative features varied and sophisticated sentence structure and diction as well as	The narrative uses some repetitive diction, simplistic language or sentence structures but mostly	The narrative occasionally lapses into casual, colloquial discourse or subjective claims at inappropriate moments. Writing	Major lapses into casual discourse or little attempt to maintain an appropriate tone. Diction is highly

	vivid details and imagery, often prioritizing showing rather than telling.	maintains an appropriate tone.	appears erratic, and some sentences are hard to follow. Writer displays an overreliance on telling rather than showing.	repetitive, and syntax is confusing. Complete lack of imagery or detail.
Grammar	The narrative is free from typographical errors as well as spelling and grammar mistakes.	A few surface errors but none so consistent that they obscure the writer's meaning.	Repeated surface errors.	No sign of editing or revision.
Total: /100				