

ENGL 105i – Extra Credit
Writing in Narrative Medicine: 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.

NOTE: This semester, I am offering two significant options for extra credit, one related to Writing in Business and one related to Narrative Medicine. Neither of these are required, but you can complete either for the chance to replace your lowest feeder grade of the semester and receive written feedback. You are welcome to complete both assignments for the practice and feedback, but only one will be available for extra credit.

Overview

This extra credit assignment is entirely optional and cannot hurt your course grade. It provides you an opportunity to earn extra credit in our class while also allowing you the opportunity to practice your skills in narrative medicine.

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.¹

—Arthur Frank, *The Wounded Storyteller*

With this assignment, you have the opportunity to put these ideas into action. You will be an 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 1,000 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 your own reflections on what such an experience reveals about larger concepts related to health and medicine.

¹ Arthur Frank, *The Wounded Storyteller: Body, Illness, and Ethics*. Chicago: U of Chicago P, 1995, pp. 53-54.

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."²

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, 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, or 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 this sort of question: 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, etc.? About the economics of healthcare? **Consider also** whether this person's experience of illness echoes any other ideas or concepts such as:

- 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"
- physician authority or fallibility
- medical personnel's tact, attentiveness, or shortcomings
- techniques of diagnosis
- social stigma
- the role of culture
- the economics or politics of health
- death, dying, and mortality

² 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.

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 sometimes integrate secondary research to contextualize or inform points made; you are welcome to do so, but you are not required to do so. 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 paper 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

How do I get started on my illness narrative?

First off, keep in mind 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 fantastic 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 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 really 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.³ (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: https://www.mcgill.ca/tcpsych/files/tcpsych/mcgill_illness_narrative_interview.pdf. This document is also posted on Sakai at Resources>Extra Credit Assignments>Narrative Medicine>“McGill – Illness Narrative Interview.”

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 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. 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.

³ Kleinman's questions appeared in Anne Fadiman's book, *The Spirit Catches You and You Fall Down*.

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 "Quick Guide to Interviews and Observations" (Sakai>Resources>Helpful Handouts and Resources).

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.

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. See also the model illness narratives from previous students, although you should note those student models are much longer than I expect you to write and involve thorough secondary research, which you are not required to include (Sakai>Resources>Extra Credit Assignments>Narrative Medicine).

Remember, you're helping to tell someone's story, sometimes paraphrasing or summarizing and sometimes using their direct quotes when appropriate. But you should also 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?

Successful illness narratives will have an engaging and descriptive title, 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, and a clear story arranged in a meaningful chronological order. 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.

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/privately], [with their full name attached/with their name (and any other identifying details) replaced, changed, or removed].

How to Submit

By 12:00pm on Tues. May 4, post your illness narrative to our course website. 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.
 - 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.
- If your illness narrative incorporates any outside sources other than material from your interviewee, your post should conclude with an MLA 8th edition format Works Cited. If those citations contain urls, activate those urls as hyperlinks for our website visitors.
- Add tags for your post.
- Categorize your post as “Narrative Medicine: 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.”

Grading Rubric for Extra Credit Assignment in Narrative Medicine: Illness Narrative

Again, since this is extra credit, it cannot possibly harm your grade. However, I encourage you to take this opportunity to enhance your grade but, more importantly, to learn and practice the skills involved in conducting interviews and composing an illness narrative, important skills for critical thinking and for a more holistic approach to healthcare and personhood in general. No matter your major or intended career path, these are skills that we should all use in our interactions with other people.

Once I assign a grade to this project, I will replace your lowest feeder grade of the semester with this grade but only if that helps your overall course average. Either way, you will receive written feedback from me on this project. Additionally, if this is a project you’d like to pursue further, I’d be happy to meet with you virtually to discuss more feedback as well.

For more information, see also Chapter 1-6: “Writing in Health and Medicine,” especially the discussions on narrative medicine, as well as Chapter 1-3: “Writing in the Humanities” in the *Tar Heel Writing Guide* as well as the various handouts on Sakai at Resources>Extra Credit Assignments>Narrative Medicine.

For more specifics regarding grading, see the grading rubric below:

	10	7	4	1
Interviewee	Writer clearly offers a holistic portrait of the interview subject that goes beyond their biomedical diagnosis; interviewee is presented in their individual complexity and is not eclipsed by their illness.	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 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.
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 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.
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				