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Narrative Medicine: Using writing to humanize medical care,
and the bodily experience of illness and death

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Honors Thesis
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As thesis advisor for Sara Lily Snoeck.

I have read this paper and find it satisfactory.

Thesis Advisor

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Therefore provide better diagnosis and treatment plans. Medical schools have become excellent at creating physicians who are highly skilled and knowledgeable in science. They have done this by increasing the demands on students to study advanced science subjects and participate in research. However, the lack of humanities education in many medical school programs over the last few decades may be resulting in physicians who are less able to connect with their patients on a human level. Through narrative medicine, future doctors and current physicians can acquire people skills that cannot be learned in hard science courses and labs.

Method and Procedures

The research for this paper is largely qualitative. Literature review of primary and secondary sources composes the bulk of the methodology. These sources include medical narratives written by doctors and patients, curriculum outlines and reflections for narrative medicine courses, classical literature used in narrative medicine courses, and journal articles regarding the practice of narrative medicine. In order to apply the use of the writing process to connect emotionally and mentally to the physical experiences of illness and death, innovative research is used that includes interviews of subjects who have used writing to cope with death and disease. These findings are then applied to the potential and documented impacts of narrative medicine. Unfortunately, quantitative research is not yet available in the field of narrative medicine; however, summaries of current quantitative research projects are used for this paper.

Findings

Writing and the writing process to help form connections between the mind and the physical experience. Narrative medicine has potential to improve patient care in the
medical setting. However, more in-depth research is needed to solidly confirm these findings.
Narrative Medicine: Using writing to humanize medical care, and the bodily experience of illness and death

Introduction and Literature Review

The practice of medicine in the modern developed world can easily become immersed in the current proliferation of fast-paced technological advances, computerized diagnostic techniques, high insurance rates, malpractice fears, specialization and subspecialization, proliferating privacy laws, and a health care system that is becoming increasingly impersonal and less patient-based. As scientific discovery accelerates, each new class of medical students must learn more medical procedures, terminology and treatment plans than the last. While these incredible advances save or improve the quality of countless lives every year, medical professionals, particularly physicians, have admittedly resorted to less personal care of patients. For decades, medical schools churned out students well-versed in anatomy, pharmacology and biochemistry. However, the faculty expected bedside manner, patient empathy, and listening skills would come naturally to students as they progressed through the curriculum and their careers.

Recently though, many medical schools have begun to search for methods to build more well-rounded physicians. Narrative medicine, a field that is in the early stages of development, encompasses the practice by doctors and medical students of writing
patient narratives, writing about their own experiences in medicine, and reading literature that humanizes medicine and disease. This paper seeks to open a candid discussion about the benefits of narrative medicine to doctors, medical and premedical students, and patients.

Narrative medicine is an emerging field, thus literature surrounding the practice is somewhat limited. However, many medical school professors and doctors have shared their experiences with and perspectives of narrative medicine. The preparatory work for this paper included a thorough review of current literature available in the field of narrative medicine. The major pieces reviewed were: medical journal articles and books regarding the use of narrative medicine in patient care, diagnosis, and teaching medicine; primary sources of doctors and patients writing about illness, death, and the human body; and classic pieces of literature dealing with issues of humanity, disease, and death which are used in medical school curriculum.

*Teaching Literature and Medicine* collaborates essays written by those who teach literature, writing, and humanities courses to medical students, undergraduates, and physicians. Contributors include medical school faculty, physicians, nurses, and undergraduate humanities faculty. Essays outline coursework and seminar topics aimed at using literature and writing to expand the skills and humanity of physicians. The pieces are meant to reinforce the idea that the “current widespread, systematic reintroduction of literature courses into premedical and medical education programs suggests a shared recognition that responsible and balanced medical education is not only enhanced by but also requires study of the humanities as well as the sciences” (*Teaching Literature and Medicine*). Various essays also include qualitative evidence of the
benefits of teaching writing and literature to medical students, and teaching methods that bring about open discussion of doctor-patient relations and medical ethics.

Articles reviewed include "Perspectives" from the New England Journal of Medicine, "Stories in Medicine: Doctors-in-Training Record a Different Type of Medical History" from National Public Radio, and "Diagnosis Goes Low Tech" from The New York Times. These articles offer examples of narratives written by doctors as well as arguments for the use of narrative writing in medical practice. The methods used by doctors to compose narratives about patients are also discussed.

A Life in Medicine: A Literary Anthology includes many of the literature pieces used in medical school humanities courses. The anthology also contains contemporary medical narratives and poetry that help doctors and health care workers better connect to their work and patients. Classic medically inclined literature such as pieces from William Carlos Williams, Walt Whitman and Raymond Carver are also included.

The anthology is built around a major 1996 American Association of Medical Colleges (AAMC) initiative meant "to assist medical schools in their efforts to educate students more fully" titled the Medical School Objectives Project (MSOP) (A Life in Medicine). This initiative identifies four attributes medical students need to acquire in order to succeed in the provision of healthcare: 1) altruism, 2) knowledge, 3) skill, 4) duty ("Report 1: Learning Objectives for Medicine Student Education"). "One goal of the MSOP is to provide a blueprint or framework upon which medical schools and educators can build unique approaches to medical education" (A Life in Medicine). Each section of the anthology begins with a description of one of the attributes and proceeds to essays, stories, and poetry that relate to it.
A Life in Medicine is a solid introduction to primary sources of medical narratives, as well as a launching point to the major literature pieces in the field. One of the most acclaimed set of published medical narratives written by a physician is The Man Who Mistook His Wife for a Hat. Written by Dr. Oliver Sacks, a physician, the collection of narratives of psychiatric patients explores personal stories behind neurological pathologies and personalizes blanket terms such as "schizophrenic" and "Alzheimer's". Several of these stories are commonly used in medical school literature courses as well as widely read by medical professionals who seek to humanize their work and better understand their patients.

A somewhat similar genre to medical narrative composed by physicians is that of narratives written by patients suffering from chronic disease. Such pieces are widely utilized by medical schools to help students relate to their patients' positions:

Patient narratives, or 'pathographies' prove especially useful because they directly introduce students to the many non-medical concerns of patients and their families. Moreover, as autobiographies that interpret and transform the experiences they record, these narratives eloquently demonstrate the importance of the physician's understanding how patients give meaning to their experiences (Teaching Literature and Medicine, 6).

The pathographies used in the research for this paper are listed on the reading lists of various medical school literature courses.

Seeing the Crab by Christina Middlebrook chronicles a woman's struggle with the reality of breast cancer. The book "begins with the frank admission that its author is doomed; she has undergone a bone marrow transplant that bought her some time but will
not, she insists, save her life” (Teaching Literature and Medicine, 285). Middlebrook offers genuine insight into the experience of a patient with a terminal illness. Passages on surgery recovery, intensive radiation therapy, and handling friends and family are both poignant and helpful in creating understanding of illness.

*At the Will of the Body* is a pathography written by Arthur W. Frank. The book entails his experiences with both a heart attack and cancer. Frank is a medical sociology professor, and thus explores the impact of life-threatening illness on one’s life and place in society. Though he recognizes the tragedy and struggle of illness, he also acknowledges the opportunity his experiences gave him to transform his life into one of purpose. He also writes that everyone experiences serious illness differently. This particular pathography not only helps readers to better understand the experience of illness, but also to recognize that it is unwise to assume patients will react in certain ways to their disease. Such a realization may be useful to those working in the medical field.

By training doctors and students in the humanities, literature, and creative writing, narrative medicine pioneers hope:

- doctors can learn to attend accurately to what their patients tell them (in words, silences, gestures, and physical findings), can reconcile the multiple contradictory versions of any given clinical story, can interpret their own emotional responses to patients, can imagine robustly each patient's plight, can adopt the patient's or family's perspective on the events of illness and-as a result of all these-can offer singularly fitting care

(NarrativeMedicine.org).
In drawing on primary sources of medical narratives, literature relating to disease and medicine, recent literature on the applicability of narrative medicine to improving patient care and diagnoses, as well as others’ reflective writing to better understand the connection between writing and medicine, a genuine connection between the mind and the body can be revealed. **The process of writing helps to humanize disease, medicine, and the physical body; specifically, narrative writing and familiarization with literature by physicians, other medical professionals, and students can create better-rounded, empathetic patient care.**

**Methodology**

Research methods for this paper involve the qualitative review of literature. Because narrative medicine as a documented process is new to patient care, research of its effects on patient care is just beginning. However, “research on the outcomes of narrative writing in medical schools is under way in a number of settings, and the consequences of narrative training for multidisciplinary health care teams are just now being tracked. Investigators are examining the outcomes of therapeutic narrative practices in the ongoing care of the chronically ill” (Charon, “Perspectives”). Such research is taking into account the cost-effectiveness of the training and extra patient time required for thorough narrative work to be incorporated into care. Because quantitative research on the effectiveness of narrative medicine on patient care quality is not yet complete, this paper will focus on how the practice of narrative medicine qualitatively affects the writers, and how writers work through illness, death, and the physical body using narrative.
Reactions of doctors and medical students to the practice of narrative medicine are well-documented in the literature, and these will be used to support the hypothesis that writing does humanize medicine, disease, death, and the human body. After a thorough review of the literature on narrative medicine, primary sources of narrative writing and other writing on disease and death were scrutinized, multiple sources of both patient and doctor/medical student creative writing were analyzed for their ability to humanize their subjects.

Two authors contributed writing for analysis and agreed to participate in an interview regarding their writing, the writing process, and how writing helped them connect to their experience with death and disease. The first author is a twenty year old female who wrote a creative nonfiction piece on the death of her grandmother. The second author is a twenty-three old male who has used writing as a way to work through his mother's death from cancer and his father's current struggle with the same disease. The interviews with these two authors were largely conversations led by the subjects; however, a list of interview topic questions may be found in the appendix.

**Results and Discussion**

During the second part of the twentieth century, advances in medical technology and pharmaceuticals, and a burgeoning bureaucracy of insurers, government programs, and healthcare provider groups dramatically increased the intellectual demands of medical students and physicians. Thus, medical schools have become increasingly science-centered, and even undergraduate pre-medicine students face heavy pressure to fill their schedules with more advanced biology and chemistry courses with the goal of
being better prepared for the intensive coursework they will soon face in medical school. However, “most medical school admission committees prefer applicants who have taken courses in humanities” (Teaching Literature and Medicine, 8). For example, the University of Washington Medical School admissions web page states: “A broad background in the humanities and liberal arts is encouraged, indeed expected” (University of Washington Admissions). Medical school faculty have realized that by requiring their students to become familiar with literature that deals with death and disease students may better become able “to imagine the other, to use the imagination as an instrument of compassion, to tolerate ambiguity, to dwell in paradox, to consider multiple points of view, and to recognize that truth about any human experience” (Teaching Literature and Medicine, 14). Other medical schools have similar expectations. Writing can further the acquisition of these qualities.

Though physicians have long written about the experiences of their patients, the practice was not widely used, nor given a formal title, until recently. Rita Charon, who has both a medical doctorate and a PhD in English, began teaching the first course in narrative medicine at Columbia University’s College of Physicians and Surgeons in 1996. “The idea came to her as an internist, when she was struck with how sickness unfolds in stories. Much of her job involves absorbing people’s stories, deciphering them and then taking action. Dr. Charon says she realized that this narrative aspect of medicine was all around her students, but never openly discussed” (Halporn). Recognizing the lack of humanities courses in pre-medical and medical school programs, Dr. Charon, who also helped create the journal Literature and Medicine published by John Hopkins University Press, found a narrative medicine course would be a useful way to incorporate
humanities, literature, and writing into the medical school curriculum. Second-year medical students at Columbia are now required to complete a half-semester seminar in humanities, and many select Dr. Charon’s narrative medicine course.

Similar courses are now being incorporated into medical schools across the nation. Most narrative medicine courses revolve around three key components: 1) the reading of classical and modern literature that incorporate bodily experiences of death and illness into their content, 2) the reading of and written response to pathographies written by patients, and 3) the composing of medical narratives by medical students. All three components are believed to improve the overall skills of physicians.

**Using literature to connect to illness and death**

Reading lists for narrative medicine courses and other humanities courses in medical schools commonly include historical classics such as pieces by Fyodor Dostoevsky, Leo Tolstoy, Albert Camus, William Carlos Williams, Walt Whitman, and Henry James. One faculty member discusses the benefits of exposing future doctors to such writing: “Literature can help us develop the ability to put ourselves imaginatively in another person’s position. If we understand, even indirectly, what it is like to be an ‘other,’ we can develop a genuine sense of empathy for such persons” (Donley and Buckley). Camus’s *The Plague* is one of the best and most widely read examples of literature read in medical school humanities courses.

*The Plague* details the occurrence of the plague in a North African town, and chronicles the observations and reactions of various characters to the epidemic that is largely ignored until it has infiltrated every aspect of the lives of the townspeople.
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Because the main character of the story is a medical doctor, several passages highlight attributes of doctors. Camus writes, “When a man is a doctor, he comes to have his own ideas of physical suffering, and to acquire somewhat more imagination than the average” (38). Through the reading of *The Plague*, doctors and medical students can better understand their position in society and in relation to their patients. It is also interesting to note that another character whose perspective is used to tell the story of the plague is a writer.

Medical school and undergraduate faculty have written on the usefulness of *The Plague* to their curriculum. Two professors who taught a course entitled *Writing, Healing and the Humanities* at University of Missouri, Kansas City write, “The novel features a variety of responses by different characters to the crisis. Moreover, it depicts social activism coupled with reflection...with issues like theses as bait, we hope to lure our students to examine what it means to be human from a perspective different from that of the biophysical model” (Spatz and Welch 142). Often it is the intricate interplay of social, humanitarian, and personal issues that make classic literature so relevant to medical education.

Reading literature can also serve as an example of successful articulation of difficult subjects. In a medical career, physicians will undoubtedly face topics and situations that are difficult for most people to discuss. In *The Plague*, “the characters, in struggling to communicate, realize the necessity of finding the right word and speaking the whole truth accurately, while recognizing the failure of words to express the fullness of thought and feeling” (Spatz and Welch, 143). By reading how characters approach difficult subjects, physicians may find it easier to articulate themselves when faced with
uncomfortable or unfamiliar situations. Reading classical literature therefore helps
students: 1) to better understand complicated issues they will be dealing with throughout
their career, 2) to see the interplay of these issues, and 3) to articulate themselves when
faced with difficult subjects and situations.

Pathographies

Narratives of disease documented by patients are perhaps an even deeper way to
connect to the physical experience. "Though not without predecessors, contemporary
illness narrative constitutes a distinctive form of life writing, a large body of texts only
beginning to be studied and appreciated...whatever texts are assigned, students will
benefit from having the apparently simple relation between illness and narrative—you get
sick, you get better, you write your story—problematic" (Couser, 282). Several
pathographies are on medical school reading lists including Stay of Execution by Stewart
Alsop, Departures by Paul Zweig, and Mortal Embrace by Emmanuel Dreuilhe. Two
pieces that will be analyzed here are Seeing the Crab: A Memoir of Dying by Christina
Middlebrook and At the Will of the Body by Arthur W. Frank.

In Seeing the Crab the reader is faced with the stark and unapologetic reality that
the author is dying. Middlebrook “actively contest[s] the marginalization of illness and
the denial of death in American culture” (Couser, 283). The book reveals the full
experience of a person facing terminal disease, stretching beyond the scenes that doctors
and medical staff are privy to, and personalizing the patient. In one passage,
Middlebrook draws on the dehumanization that can occur to patients in hospitals:
I cannot forget walking, fully alert and unmediated, into that stark operating room. I can see the stainless steel table where I would soon lie inert, useless and messy like a discarded cafeteria tray, abandoned until the menial housekeeping staff would clean me up. The nurse offered me a little stepping stool, but I was so wired I boosted myself right up onto the table. The flimsy hospital gown fell open at the front. The room was cold. I shivered and no one cared (Middlebrook, 8).

Reading such vividly written experiences can help medical students and physicians to understand the vulnerable position patients often find themselves in. Such an understanding could lead to a higher quality of patient care as physicians become more empathetic toward their patients.

Middlebrook also offers insight into the most physical part of a patient’s experience, pain:

Joy in the midst of pain is everything. Transplant pain is with me everyday: bone pain, joint pain, foot pain, esophageal pain, headaches, earaches, jaw pain, edema pain, tooth pain, bruised shins, difficulty swallowing, difficulty eliminating, heart fibrillations, shortness of breath, fatigue, fatigue, fatigue. I wake at night wide-eyed with pain in my thigh. 911 pain. The next morning it subsides. My feet don’t work, plain and simple. I’d give all my new clothes, the CDs, the voice mail, and the new windows for a new spine . (Middlebrook, 166).

Passages such as this facilitate a deeper comprehension of the daily sufferings of the sick.
In her discussions of the medical community, Middlebrook emphasizes the importance of a returned phone call from a nurse, the extra seconds a physician takes to perform a physical examination before writing a pain prescription, and other small acts that succeed in making the patient feel human. *Seeing the Crab* and other such patient narratives serve as a sort of comment card for doctors and hospitals, and as a reminder that the patient must live with their said condition twenty-four hours a day, not just the hours spent in medical settings. Middlebrook writes, “Intellectual understanding pales before experience” (Middlebrook, 192). Because many physicians have not experienced chronic disease, pathographies may be the best insight they can have into such conditions.

*At the Will of the Body* is beneficial to medical education in similar ways. Frank is blunt with his bleak experiences. His book begins, “I have experienced life-threatening illness twice. I had a heart attack when I was thirty-nine and cancer at age forty” (Frank, 1). Frank also expands on the important responsibility physicians have to communicate well with their patients:

Physicians too often do not express to the patient that they recognize her experiences of fear, frustration, and personal change. Their talk is about diseases, about the parts that have broken down, not about the whole, which is living the breakdown. But physicians’ self-imposed limitations dictate the reciprocal roles patients are expected to play in responding to physicians (Frank 12).
Memoirs such as Frank’s can help medical students and physicians to understand the barriers erected between physician and patient, and the importance of fostering some sort of dialogue with a patient beyond medical and technical jargon.

Though many physicians have not experienced actual life-threatening illness, patient narratives can be an affective method of fostering understanding of the experience of illness in a patient’s life. Through reading patient narratives, students and doctors: 1) can view a sort of “comment card” or patient evaluation of their experience with the medical field, 2) better understand the vivid experience of illness, pain, and death, and 3) facilitate dialogue with patients that helps patients to emotionally and mentally connect to the illnesses and pain that are inflicting their bodies.

**Writing as a tool**

While reading about disease, death, and their effects on humanity is an effective way to improve the empathetic and patient skills of doctors, other health professionals, and medical students, some medical schools and hospitals have found writing to be an even more useful tool. When Dr. Charon began her exploration into literature she realized that “the more she read, the more parallels she found between the stories she was reading and those unfolding in her medical practice” (Mangan). She began to experiment with writing narratives about her own patients. Like any creative outlet, writing can help with coping and understanding the difficulties one faces in life. The writing of narrative naturally follows the story line of illness:

Conceptually, medicine offers the scholar a family of narratives generated by illness—the sickness itself as inscribed on and in the body, the patient’s
autobiographical account, the account as transformed by the doctor’s cataloging mind (trained to be both arrogant and afraid of chaos) and written down, and the course of the illness itself—that exposes uncanny and telling relations among language, soma, self, and time (Charon, 30).

The program Dr. Charon implemented at Columbia University’s College of Physicians and Surgeons requires third year medical students to keep “parallel charts” of patients. Students keep a standard hospital chart that uses technical lingo to describe a patient’s condition and treatment. However, a second “parallel chart” is an “essay that uses everyday language to convey a student’s emotions and experiences in working with the patient” (Mangan). Keeping a parallel chart is thought to improve the listening skills of future doctors. “The work of medicine in considerable part rests on the doctor’s ability to listen to the stories that patients tell; to make sense of the often chaotic narratives of illness; to inspect and evaluate the listener’s personal response to the story being told” (A Life in Medicine, xv). Parallel charts do just this.

Medical students are finding the practice of maintaining parallel charts does help them to draw more information out of a patient. Rather than proceeding through a standard list of medical history questions, some students are finding they learn more useful information from a patient by simply saying: “Tell me about yourself.” Medical history questions may help physicians to learn what medications a patient is taking, what surgeries and diseases they have undergone, and what genetic diseases are in their family, but a narrative approach may reveal that an arthritic woman works two minimum wage jobs to support her family and cannot afford proper care and rest to treat her condition.
Narrative medicine makes the patient’s life story a part of his or her illness and potential treatment.

Dr. Charon recalls a patient who came to her with a backache. By asking him to tell her about himself, she learned that he was illiterate, about to be laid off, had a possible learning disability and mood disorder (Mangan). Such background information may lead to a different diagnosis and treatment plan than if Dr. Charon had only asked about what medications he was taking for his pain. Dr. Charon calls this increased ability to listen to and understand a patient “narrative competence” (Teaching Literature and Medicine, 6). “This competence requires a combination of textual skills, creative skills, and affective skills” (Charon, “Perspectives”). The acquisition of these skills, which are often overlooked in formal medical education, create more well-rounded physicians.

In order to meet the rigorous demands of a medical school education, students often disassociate themselves mentally and emotionally from their work and the human body. LaVera M. Crawley, a medical student, recalls her experience in a sophomore pathology lab where students examined a human heart specimen with a ruptured chorda tendineae. The students did not learn until later that the heart had once belonged to a former student of that same medical school. “The story’s irony is reinforced by a medical education process that had thought it necessary to depersonalize the human body in order to teach basic sciences” (Crawley, 316). This phenomenon may be most apparent in the language of students, who often struggle to use emotive, everyday language with their patients. Thus, it is easier to label a “ruptured chorda tendineae” than describe the wrenching story of a bright, young man collapsing while playing basketball.
Medical terminology is really nothing more than a technical system of semiotics. However, signs “can signify some second level of meaning, and it is here that narrative can play a role. The distorted red cell we see not only refers to an abnormal hemoglobin state but also can…[be] suggesting a story of suffering and a lifetime of chronic, agonizing pain faced, perhaps, by an African-American child” (Crawley, 320). For quality and affective patient care, it is vital that future doctors learn how to see both levels of signs.

Stephen Lee-Kong, a Columbia medical student in Dr. Charon’s narrative medicine course watched a video tape of himself with a patient as he struggled to discuss her condition with her. “Drawing a patient out isn't always easy, as Mr. Lee-Kong discovers when he inadvertently lapses into medical-speak with the woman in his care. When he asks whether the pain is radiating through her abdomen, she looks confused, and a little annoyed. ‘Radiate?’ she repeats in a strained voice” (Mangan). However, keeping a parallel chart helps students to be able to reach beyond medical terminology when talking with patients, and maybe even understand their own emotions as medical professionals and caregivers.

Rose Susan Cohen, another Columbia medical student, kept a parallel chart of a dying elderly woman. The following is an excerpt from that chart:

‘Altagracia. I am obsessed with her first name. ... I imbue her name with spiritual, romantic, and mysterious overtones,' she writes. ‘Yo se que yo voy a morir en el hospital.' I know that I am going to die in the hospital.' Clutching her wrinkled face, which droops on the left, with her tendinous, wasted hands ... she looks at me through her claw-like fingers. She's
childlike, hidden.

Failure to thrive. ... She won't eat. She kicks, she hits, she clutches and bends your fingers. ... No, you can't open her eyes to shine a light, and you can't open her mouth. She's hiding from me, deep inside her body. (Mangan).

Medical students and physicians are rarely allowed to open themselves to such introspection of a patient. But doing so allows them a greater connection to not only their patients, but to disease, death, and the human body—the work and life of a medical professional.

Writing medical narratives can also help students and physicians to evaluate the quality of their care for a patient. In a sense, the writing of a medical narrative helps doctors to take a step back from their “professional” role and see a case from the view of the patient or the patient’s family. This in turn helps doctors to objectively recognize their strengths and weaknesses as a medical professional. In the following excerpt from a narrative written by a medical student, the writer/student confronts his own fears of informing a patient that she could have a serious disease:

Mrs. V., who came to us because of severe back pain and blood in the urine, asked me several days later whether she had cancer... I told her that I didn't think she had cancer, but that it was one of the things we would look for and rule out in subsequent tests. I may have even told her to let us worry about it for her. She was pleased. Had she not said it first, I would not have used the word cancer in our conversation. The word forced me to
be more specific than I wanted to be with a paucity of information at the time (Halporn). The student continues with his narrative and admits that he is "still anxious" for her final biopsy result (Halporn). He may not have consciously admitted his own fears to himself if he had not written about the experience. Thus, narrative medicine can serve multiple functions. Perhaps, however, the greatest benefit of narrative medicine is its ability to restore the doctor-patient relationship to one of trust and mutual concern. Physicians who practice narrative medicine learn to read their patients' every word, movement, and pause. When a doctor practices medicine with narrative competence, he or she can quickly and accurately hear and interpret what a patient tries to say. The doctor who has narrative competence uses the time of a clinical interaction efficiently, wringing all possible medical knowledge from what a patient conveys about the experience of illness. Narrative medicine is currently undergoing quantitative research on the effects of narrative medicine can be studied, quantitatively. Though much qualitative and anecdotal evidence of the benefits of narrative medicine is available, little research has been done to study its effects. Quantitative research on narrative medicine must take into account the many factors, including the disadvantages of narrative medicine. The practice is both more costly and time-consuming than the simple use of medical histories and patient surveys. Doctors must spend more time with a patient to compose a comprehensive narrative of the patient's experience. The practice is also likely to be more specific than I wanted to be with a paucity of information at the time (Halporn).
increased time, thus physicians and hospitals would have to bear the extra labor and paperwork costs.

Narrative medicine also carries the risks of allowing physicians and other medical workers to become too emotionally attached to their work and patients, and thus less able to apply objective diagnosis and treatment. For years medical schools have sought to create doctors who are emotionally detached from their work, so that decisions may be made quickly and clinically. Many doctors are already overburdened with their patient load, and the practice of narrative medicine would further stretch their limited time. This could spawn a cycle of fewer patients receiving care from a physician, which would likely mean the further squeezing out of patients on Medicare and Medicaid from the mainstream healthcare system.

Another pertinent issue in the modern American healthcare system is privacy. As doctors increasingly embrace the entire process of narrative medicine, sharing of medical narratives will become more common. If a patient has not given permission for their narratives to be shared, a breach of privacy will occur. The above items must be taken into consideration in any quantitative research that is evaluating the effects of narrative medicine on both patient care quality and skill and capacity levels of medical professionals.

Current research regarding narrative medicine is taking place in multiple healthcare settings. One study is tracking the use of parallel charts by medical students in their third year internal medicine clerkship at Presbyterian Hospital in New York. Thus far, researchers have concluded that “the practice of writing and reading led to frank and helpful discussions about the emotional, ethical, and personal levels of care”
The research is not yet complete; however, "Preliminary findings reveal that... students who wrote were found by their faculty to develop better therapeutic relationships with patients and to be more effective as medical interviewers...[and] evaluated themselves as more confident than those who did not in such clinical capacities as caring for dying patients and giving bad news" (NarrativeMedicine.org). Examples of students who used narrative writing to hone these skills are cited earlier in this paper.

Narrative medicine is also being incorporated into the oncology unit at Presbyterian Hospital. Doctors, nurses, and social workers have begun a pilot program where they write about their daily experiences with patients and gather to share them twice a month. After the first year of the program, participants are very enthusiastic about the use of "narrative oncology" and are currently seeking funding for a major clinical outcomes study on the effects of narrative medicine within the unit (NarrativeMedicine.org).

Research is also being conducted to evaluate the effectiveness of increasing humanities education for future doctors. "The study, funded by the National Endowment for the Humanities, will attempt to clarify the conceptual underpinnings of humanities teaching in medical settings and then to rely on that conceptual framework to design a narrative training program for health professionals" (NarrativeMedicine.org). Project leaders are from multiple disciplines in university settings and hope to develop a pilot training program for medical education faculty that focuses on narrative writing as a path to better patient care.
The publishing of quantitative research that verifies the benefits of narrative medicine, creative writing, and humanities education to the medical community will hopefully lead to increased usage of writing and reading in medicine. However, writing has shown therapeutic qualities not only for medical professionals, but for lay people experiencing death, disease, and the physical reality of their own human bodies. This paper will now turn to an analysis of two such people, their writing, and the writing process that helped connect the mind and the body and humanize medical and bodily experiences.

**Writing about cancer**

Travis, a 23 year old, has used creative writing as a method to understand his experiences with terminal cancer. At age 15, his mother passed away due to cancer. He has written about her sickness, her death, and his own life and emotions after her death. Writing has been a way for Travis to express his own emotions regarding her death, including sadness, anger, and confusion. Through sharing his writing in college creative writing courses and workshops, he has partaken in conversations about losing a parent and the emotions that accompany such an experience. One course that was particularly useful to his writing process was a poetry workshop that included several students and an instructor that were also writing about losing a parent. Students were able to empathize with each other in a way very similar to groups of doctors and other medical professionals who meet to share their patient narratives.
In a poem entitled “Thank You,” Travis writes about the reactions of others to him losing his mother. He writes, “The permanence hit me the hardest/It demolished my brain daily/and wetted my face as I kept it low and/behind my hat brim./I spat out my swallowed tears and tried/not to think/about you not being there for my/graduation/or my wedding/or to hold my first born” (Dutton). Through writing the poem Travis better recognized his anger at others for their seemingly meaningless reactions to his mother’s death, as well as his own struggle to tell others what they wanted to hear: “and I wanted to show them the pieces of brain in my head that were in the/thousands,/no longer connected or certain of/anything,/and ask them why I didn’t need you/anymore” (Dutton). For Travis, losing his mother is something he deals with everyday, not just on the day of the funeral or when he has an occasional passing memory.

In “Chicken Dinner,” Travis admits his inability to speak at his mother’s funeral and share his memories of her (Dutton). In another poem, Travis compares being at his mother’s funeral to “walking though school hallways/waiting for the bully to call me out…” (Dutton). Metaphor is a method of not only better understanding one’s own experiences, but of achieving better communication with those who have not been through the exact same experience. In listening to patients while writing narratives, metaphors may be useful for physicians to put their patients’ experiences into context.

Travis has also written much about the years before his mother died, when she was suffering from terminal cancer. Here, his writing process serves as a catalog of his memories of his mother as well as his own changing emotions throughout her sickness. In “Pineapple,” he writes about his family’s last vacation with his mother. “It was our last family trip/I did not know it then./Paid for by friends and family/who knew it./I think the

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2 See appendix for full poem.
man selling pineapples/on the road side knew/too” (Dutton). Pineapple becomes a
metaphor for the change in his life. He does not like the pineapple in Hawaii, but it tastes
good later, at his mother’s funeral. This is not to say that he likes the change of losing his
mother, but that it became real for him.

Travis discusses his mother’s physical symptoms in an untitled short story. He
also writes about his own reactions to these symptoms. The story is about one morning
when his mother was not wearing her wig to cover her scalp, balded from chemotherapy.
He does not want to see her without the wig: “If I come out of my room now I will
explode. I will die. I will cry. Something bad will happen if I look her in the face and see
how skinny and vulnerable she looks” (Dutton). He also applies his mother’s wearing of
a wig to society’s handling of the severely sick or disabled: “Blind people put on
sunglasses, fat people wear baggy clothes, rich people change channels on starving
children, homeless people stay under bridges and dying people wear wigs” (Dutton).
Here, he is able to connect his personal experience to that of humanity in general.

Though Travis graduated with a degree in English, he has continued his writing
since his father was diagnosed with throat cancer. No longer in college workshops where
he can share his writing on a weekly basis, writing has become more personalized for
Travis; yet the writing process still serves the same purpose of helping him to
emotionally connect to physical experiences. In an untitled essay he illustrates his
father’s experience with cancer: “My father dredges his body at dawn. I can’t sleep
through the progression of whooping coughs gaining higher and higher pitch to the
abdomen forced wretch clearing the swampy liquid from stomach to lungs to throat to
mouth and finally to the sink where it lands with a marshy slap and flows, congealed into
the drain" (Teaching Literature and Medicine). Travis works with water conservation on rivers. By relating his father’s sickness to his own life, Travis is attempting to connect his own humanity to his father’s disease.

Having suffered the loss of one parent from cancer, Travis is able to use his writing to connect to his fears over having a second parent diagnosed and treated for cancer. Through writing, Travis has an outlet for his intense emotions and inner reactions to his parents’ illnesses. The writing process has helped him to work through years of disease and death; however, writing can also help a person understand a solitary experience with death or disease.

**Writing about death**

Katie, a 20 year old female, has written a short story about the experience she had with her grandmother’s death. Katie was with her grandmother during the last few days of her grandmother’s life. Her story chronicles the last stages of the dying process, and describes the physical and emotional aspects of death in great detail:

> Entering room 210 I saw a frail figure occupying the bed. This couldn’t possibly be my grandma. It was an old grey-haired lady. Her eyes were completely shut and there were tubes running out of her nose. Her checks were sagging down on the pillow fully revealing the lines of her check bones. Her arms were a dark purple and all of her skin just seemed to hang there liked squished prunes. To me her body seemed liquefied. Attached to the side of the bed was a clear plastic bag containing urine (Rae).
When discussing her piece, Katie acknowledges her writing process served to make her experience more real to her. "As I wrote about it I thought more about every little detail. It was a blur as it happened, but writing made it more real" (Rae). In a similar manner, narrative medicine is meant to help students and doctors to slow down and understand their experiences with illness and death.

Another common attribute of medical narrative writing is its ability to help writers confront their own fears and discomforts regarding difficult situations. Katie writes: "I couldn’t handle suffering right then. I was more scared than I had ever been in my entire life" (Rae). Writing has helped Katie to not only acknowledge these emotions, but to accept them. She states, "Writing helps you understand what you are feeling because I was confused at the time" (Rae). By taking personal moments such as her family’s reciting of the Our Father during her grandma’s last breaths, Katie is able to connect with emotions she was unable to understand at the time of her grandma’s death.

A few months after writing this piece, Katie had a similar experience when her good friend passed away after a motorcycle accident. Again, she spent days in the hospital with him before his last moments. Because she had taken the time to write about and understand her reactions to her grandma’s death, Katie believes it made her reactions and emotions surrounding her friend’s death easier to understand. The writing process forces writers to articulate feelings they may not even have realized they had. Because most doctor’s will repeatedly experience serious illness and death with their patients, writing can help them to move between such situations with more awareness of both their and their patient’s emotional processes and reactions.
Conclusion

Narrative medicine and the writing process have great potential to help those who experience illness and death to connect mentally and emotionally to physical experiences that humans often emotionally separate from. As a result, patients and medical professionals can better understand and cope with the weaknesses of the human body and work through the trauma, chronic pain, and devastating loss that stem from disease. Currently established curriculum for narrative medicine courses in medical schools and pre-medicine programs focus on: reading classical and modern literature that pertain to social, philosophical, and humanitarian issues related to the field of medicine; reading patient and doctor medical narratives; and writing responses, medical narratives, and parallel charts. These three spheres encompass multiple forms of knowledge and skill that serve to improve patient care.

In a more general sense, writing can be a therapeutic method for many people to work through either their own illness, or the illness and/or death of those they are close with. Illness can often be an isolating and depersonalized experience. The writing process, however, can humanize and personalize the experience.
Bibliography


Rae, Katie. Personal Interview. 15 July 2005.


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Appendix
Narrative Medicine Curriculum

Reading Literature
- Increases understanding of societal, humanitarian, and philosophical issues relevant to medicine.
- Helps build understanding of how these issues interplay.
- Increases articulation of difficult subjects and issues.

Reading Patient Narratives
- Serve as patient "comment card" or evaluation of medical care.
- Increases understanding of the patient experience with illness and death.
- Facilitates dialogue with patients.

Writing Medical Narratives
- Increases listening skills, and quality of treatment plan and diagnosis.
- Improves physicians' ability to relate with patients.
- Helps physicians and students to confront personal discomforts and emotions.

Figure 1
Interview Script
Narrative Medicine: Connecting Writing to the Physical Experience

Discussion will largely be directed by subject. Discussion will focus on the following questions/topics:

1) Tell me about your writing.
2) Have you used writing as a way to connect to your emotions regarding illness, death, and/or your physical body? Do you feel writing helped you “work through” these things?
3) What compelled you to write about these topics?
4) Tell me about the writing process you went through.
I stood in the doorway of room number 210. My mother and I had come to the hospital for the last time to thank the nurses for their kindness. The bed taking up almost the whole room was empty. There was nothing left in the room but a finished puzzle and a deflated balloon reading, “Get well soon Grandma.” I stood staring at the lifeless room. The room was indescribably eerie that morning. As I shut the door and turned to leave, my mother stepped away from the help desk and said, “Come on Katie. It is time to go.”

It was a cloudy Monday morning when I awoke to the phone ringing. I rolled over to look at the clock. It read 5:30. “Who would be calling at this hour?” I thought to myself. I remembered that about a month earlier we had received an early phone call letting us know that my grandfather was going to pass. I threw my red down comforter off of me and crawled out of bed to find if the phone call was for me. Entering my mother’s bedroom, I saw my mom sitting in her bed patiently listening to the caller. Her face immediately changed to a scared shade of white. “Okay, I understand. Just please keep me updated on her condition. Thank you. Bye,” my mother conveyed and then hung up the phone.

“Mom, who was that? Is everything okay?” I questioned.

“That was Grandma’s nurse and she says that Grandma isn’t doing well. They moved her to the hospital tonight.”

“Do you have to go back to Missouri again?”

“Probably. The nurse is going to let me know if she gets any better. If not I will probably leave on Wednesday.”
“Well, I will go with you if you want.”

“You might have to. I don’t think that your dad will be able to come with me this time. But don’t worry about it today we will figure it out later.”

“Hey. I love you.”

“I love you too.”

As I walked from the dark bedroom I realized that through that whole conversation she never shed a tear. I wondered if it was because she didn’t care or if she never loved her mother.

We sat on the runway for what had seemed an eternity. The nurse had called back a day later and told my mother that her mom probably only had a few days left to live. So here we were on our way to my parents home state of Missouri. My mother was right and my father was unable to make the trip. It was one of those trips though, that a person could never make alone. My mother clung tightly to the arm rest and there was a silence between us. Going through my mind was, is this plane going to make it to Missouri or are we going to die? Looking over at my mother, I wondered what thought was making her so tight. Was it the fact that her mother was dying, or was it that she didn’t want to be doing this or was it simply the same thing that was plaguing me? Either way my mother’s face held no sign of a smile or even any emotion. It was still as white as it was two mornings ago when she received the call. The plane finally entered the sky and I saw my mother make the sign of the cross. I too hoped that our plane would make it to Missouri and that everything would be okay.
We grabbed our bags from the oval baggage claim carousel. Walking out of the big automatic glass door, I noticed the sign above the door, “To Rental Cars Enjoy your stay in St. Louis.” It had been an entire three years since I had been to St. Louis. The last visit was meant for my sister and me to see our grandparents before they passed away. Out of all 4 grandparents, it was weird that it was Grandma Ruth that was dying. She had been the one in the best condition. When we visited her at the nursing home three years back, as soon as we walked in her bedroom she sat up out of her small single bed and said, “This is a surprise. Christine didn’t tell me you were coming. I am glad to see you.”

My mom and I got into our rental car, a small, gold Hyundai Elantra. “Hey Katie look! It has a sunroof,” my mom exclaimed, finally showing some sort of emotion.

“That’ll be useful considering it’s like 20 degrees outside right now,” I remarked.

As we drove the car out of the parking garage, wet snowflakes hit the windshield. We took the first exit onto the interstate and to the left was a sign, “St. Charles 50.” We had just about an hour to gather ourselves for what we were about to encounter. Silence invaded the car and it lasted until, “Are you hungry, Katie?” my mom asked.

“I could eat,” I replied.

We pulled into Steak and Shake. Every trip to Missouri that I can remember involved a Steak and Shake. It became a tradition. But this time was different. We wouldn’t be bringing a chocolate milkshake to my grandma. Though, just like every time before I ordered the chili mac and cheese fries. The burger that my mother ordered just sat in the bag never being touched. I guessed that my mother was too nervous to eat.
Our car pulled into a midsized town along the river. To the right of us was a huge river boat with overwhelming lights flashing about and a sign reading just one lonely word, “Casino.” “Since when did Missouri have Casinos?” I curiously questioned my mother trying to break the silence.

“Since they changed the law,” my mom answered. “Hey look! There is my old high school, St. Charles High.”

The building was made of big stoned and tall glass windows. Behind the building were a football stadium and a press box decorated with a mural of a pirate. The car finally came to a stop in front of the St. Charles Hospital. This building was old as well but on the back of it was what looked to be construction or remodeling. The elevator took us to the second floor. Entering room 210 I saw a frail figure occupying the bed. This couldn’t possibly be my grandma. It was an old grey-haired lady. Her eyes were completely shut and there were tubes running out of her nose. Her checks were sagging down on the pillow fully revealing the lines of her check bones. Her arms were a dark purple and all of her skin just seemed to hang there liked squished prunes. To me her body seemed liquefied. Attached to the side of the bed was a clear plastic bag containing urine. A man was sitting in a rolling chair in the corner next to the bed. “Hi, I’m Jeff. You must be family,” he said standing up.

“Yes, I am her daughter Chris and this is my daughter Katie,” my mom introduced herself.

“I’m Ruth’s nursing assistant.”

My mother walked over to the bed and took my grandma’s hand. My grandma’s fingers were a dark shade of violet and the skin shriveled around the bone.
“Hi mom. It’s me Christine. Katie and I came down to see you,” my mother rubbed her straw-like grey hair. Her eyelids popped open and cloudy blue eyes looked up at my mother’s face. A loud moan came from my grandma’s toothless mouth but was softened with the gentle touch of my mom’s hand on her forehead. My mother just smiled at her mom, “I know, mom. It’s okay,” still no tears emerged from her glazed over eyes. I took a seat in the corner by the small shaded window. I sat watching my mother treat my grandma the way she had always treated me; like a child. It’s weird how as a person grows up, they trade places with their parents. I hoped that I someday would have the same compassion for my parents as they had for their parents.

A few years back when we had made the trip to visit all of my grandparents, I remembered my father’s reaction to his dad. It was a bright sunny day in Washington, Missouri. We stopped at a nearby bakery before heading up the big green hill to the nursing home where my grandfather lives. Our rental car pulled in front of the giant Victorian building and we entered through the automatic sliding doors. My grandfather was sitting in his wheelchair staring out into the garden. My father walked over to his chair, rubbed his white frizzy hair and said, “Hi dad. The girls and I came to visit you. Do you want to go outside to the garden?” My grandpa looked up at him, then at my sister and me. Then without saying a word, he turned back to the window. My father took his wheelchair and wheeled it out to the garden. The sun beat down on my grandpa’s pale face. My dad trying to lighten the mood said, “Hey Dad, look, we brought you a donut. It’s cream filled, just like you like it. Don’t tell the nurses. They may never let me come back,” my grandfather just continued to look at the sun.

“Dad, remember what you used to think your name was?” asked my sister.
“Oh yeah. Dad, do you remember what I thought my name was until I was 12?”

My father looked at my grandfather hoping for an answer and knowing he wouldn’t get one. But my grandfather just sat there with no expression soaking up the sunlight and fresh air.

“I thought it was shit-ass dad,” my father answered his own question. My grandfather finally let out a little smile. My father was trying so hard to communicate to his father. I felt a tear hit my chin and I knew that it was my time to leave. I didn’t want my grandfather to know that I was feeling sorry for him. I grabbed my sister’s arm to leave and walked away. I could hear my father behind me, “Oh dad. I hope that you are alright. I wish you had never broken your jaw. I love you dad.”

I looked back at my mother and grandmother. My mother just continued to caress her head and told her about how our trip was. I left the room and left my mother alone to comfort my grandmother. I walked into the waiting room and sat down to watch Fresh Prince. I saw a pile of games sitting on the table next to the couch I was on. I picked up the box that was held together by tape and walked back to room 210. My mother looked at me, “What did you find?”

“A puzzle. I figured it’d keep me busy,” I answered.

“Well, good. We are going to stay here for about an hour and then we’ll go to Aunt Joan’s house.”

“That’s fine. Don’t worry about me. Take as much time as you need.”

For some reason, even though I have always been impatient, it didn’t matter to me today. Nothing mattered to me. I sat down at a little fold-up T.V. table and dumped the
puzzle pieces on the table. Every piece looked the same; white with black spots. I knew
the puzzle was going to take a while. As the strenuous puzzle hour slowly trudged by,
my mother sat right next to my grandma rubbing her head. We left that night from the
hospital still seeing the pain and suffering in my grandma’s face. I knew that this week
was going to be long week.

As I crawled into bed that night, I prayed that God would take my grandma that
night. Seeing her that day in that condition, I knew that she had nothing left to live for
and she had suffered long enough. But when we woke in the morning, we hadn’t
received the call. We left the house about 9 am that morning and trekked off the hospital.
I continued my puzzle piece by piece, starting with the outside and working my way
towards the center. My mother continued to talk to my grandma. The mood was finally
broken when my uncle, my grandma’s brother and his wife entered the room. We sat
around my grandma reminiscing about passed “Ruth and Pat episodes” (my grandma and
grandpa). I could feel the presence of my grandma in the room but as we talked, it was as
if she wasn’t there. It felt more like we were in a living room just sitting there chatting.
Ten hours we spent at the hospital that day. The entire time we all knew what we were
doing. We were just waiting for her to pass.

Three days went by and each night I prayed that the next day would be the day. I
knew that I was trying to help my grandma. I just didn’t know why I spent that time
praying to God. I had always been semi-religious but praying every night was something
I rarely did. Each day I worked on my puzzle, piece by piece. The farther I got, the
harder it became. The third day, we spent the longest time at the hospital. I sat at my
T.V. table and anxiously worked on my puzzle. My mom sat in the chair right next to my grandma.

"Katie, I guess we should go soon and eat dinner," my mom suggested.

"I think we should stick around for a little while longer. I just have this feeling," I replied, looking up from my puzzle.

I didn’t know if it was just that I really wanted to work on my puzzle or if I really had an enlightenment telling me that we should stay. Either way we stayed. We stayed until the night nurse came on duty. I sat working away at the puzzle and my mother fell asleep with her hand on my grandma’s hand. As we finally got up to leave I turned to my grandma once again hoping that she would go tonight.

That night I dreamt that my grandma had passed and everyone was happy again. However, when I awoke, there was still no call and no signs showing that she had passed. My mother and I headed to the hospital early that morning. On the way we stopped by the nearby King’s Market and bought a white daisy plant for my grandmother. We walked into the vaulted ceiling lobby and stopped at the two elevators on the left. I pressed the button and we waited for the elevator to hit our floor. The elevator came to a stop at the second floor. We stepped out and straight ahead of us was room 210. The room was lit by the sun which was shining through the open shades. The nurse had just prepared my grandma for the day, “Good morning. I am Cindy and I will be Ruth’s nurse for today.”

“I am Christine, her daughter and this is Katie, her granddaughter,” explained my mother.

“She looks pretty good today. You know, peaceful like.”
“She does, doesn’t she?”

“I have been taking care of Ruth for a while now. She is a very sweet patient, even in her comatose condition.”

“Thank you so much for taking good care of her. She needs it right now with how much pain she is in. Her cheeks look like they have puffed up a little bit more.”

“Oh, yeah, they do,” the nurse pressed on the cheeks and my grandmother squinted her face up as if she had been punched.

I knew how much pain she was in. It was like no pain I had ever experienced in my life. I sat down once again to work on my puzzle. I noticed that it was so close to being done. There were only a few more pieces. I continued to try to fit the pieces together and my mother took her spot in the chair next to my grandma for the fourth day in a row.

“Mom. We left the flower in the car,” I told my mother.

“Oh that’s okay. We will just bring it to her tomorrow,” my mom said optimistically. As I went to fit the last piece into the puzzle, I realized that the piece was missing. I looked around for it but the white and black spotted piece was nowhere in sight. My grandma’s heartbeat machine began to beep and my focus immediately shifted towards the bed. My grandma began to struggle and roll around on the white sheets. Her shriveled fingers kept reaching for the feeding tubes. My mother ran out into the hall, “Hey nurse, I think that you should come in for a second.”

‘Is something wrong,” the nurse said running into room 210. “It looks like she is having a hard time breathing. Let me go get an oxygen mask.”
My grandmother's struggling became worse and worse. The nurse quickly returned with an oxygen mask and strapped it around my grandma's slender and wrinkly face. My grandma's eyes opened at focused on my mother's face.

"Katie, we need to call Uncle John and Uncle James," my mom anxiously told me. She grabbed her cell phone and dialed the number. “John please pick up. Please pick up...John? I think you should get down here as quick as you can. She isn't doing very good. Okay, I will see you soon.” She then proceeded to place the second call, “Hi Uncle James. It's me Christine. Mom is not doing very good. She is failing quickly. I think you should try to come down here. Be careful though, the roads are slick. I'll talk to you soon."

My mother sat next to my grandma tapping her foot nervously and rubbing my grandma's head in order to calm her. I forgot about my puzzle and stared out the window instead, trying to avoid watching my grandma. I had never experienced someone suffer like she was. Her blue eyes looked about the room as if she was trying to see life for one last time. She wasn't letting go, though. She continued her struggle, throwing her arms about and breathing heavily. “It's okay. Mom, we are here for you. You aren't alone. It's okay you can let go. Dad's waiting for you," my mother said to her mom.

“Grandma, it's okay. You had a great life and you can let go of it,” I told her still gazing out the window as tears ran down my face. I couldn't take my focus off of the window. I was looking for my uncles' cars and was also trying so hard to not see her suffer. I couldn't handle suffering right then. I was more scared then I had ever been in my entire life. “Katie, you can touch her if you want. Let her know that you are still here for her, my mom suggested.
My hands shook as I finally reached for my grandmother’s hand, still trying to not look at her body. I finally laid my gaze upon her. Her facial expression was one of strength and determination. She was waiting for something. There was some reason that she wasn’t letting go. I put my hand on her forehead. I could feel her veins tense up. Her cloudy eyes looked upon mine and she let out a slight moan. She knew I was there. She knew that she wasn’t going through this alone. I looked one last time out the window and saw my Uncle John’s red convertible Le Baron pull into the visitor parking lot. “Your son is here. Mom, John is on his way up right now,” mom exclaimed trying to comfort her mother.

John entered the room out of breath. He stepped up to the bed and looked over my grandma’s body. She looked at him, and gave another moan but continued to struggle. “Mom, I love you. Thank you so much for everything that you did for me. I couldn’t have asked for a better mother. I love you,” my uncle told her.

“Mom, I love you too. You gave me a great life and let me have many opportunities. I thank you as well for everything that you have done for me. Now, let go. Dad is waiting for,” my mother chimed in.

“Alright mom. Let go. We love you and we are here for you.”

She still continued to struggle. She had complained about living her whole life, and now at the end when she was suffering the most, she didn’t want to let go. She was still waiting for something. For some reason she didn’t want to let go. Maybe she was scared. Maybe she changed her mind and she wanted to live longer.

Her brother James finally walked through the door with his wife Louise. He saw his sister’s frail body, struggling about the bed. He saw her trying to hold on to every last
second that she could. She looked up at him as he grabbed her hand, “Shhh... Ruth, you’re okay. I love you.”

At that moment her body seemed to limp. Every muscle in her body relaxed. She laid there taking her last few breaths. I knew that what made her live was gone. Even if her body was still functioning, there was no soul to actually to give it life. I realized that it was true. When a person dies, their soul leaves right before they take their last breathe and watches themselves pass away. I could feel her presence above me. I could feel God’s presence all around. I truly got the chance to experience God, and I believed. I understood why I had prayed; God is the last person to be there in the end.

We all grabbed hands around my grandma and prayed The Our Father. At the end of the prayer, I smiled and watched her take her one last breathe. I looked around at everyone else and there was peace among the entire crowd. Each person knew that she was no longer in pain and she was finally were she belonged, where we all belong. I walked over to the top of the bed, rubbed her forehead, kissed it and whispered one last time, “goodnight grandma. I love you.” Still to this day I don’t know how I was able to touch a lifeless body. But at that moment, in that room, there wasn’t any fear and there wasn’t any sadness. There was only peace. We all congregated around the bed and hugged each other, a smile on each and every face. A sheet was pulled over the body’s head after we said our final goodbyes. As I started to walk out of the room, I noticed my missing puzzle piece under the bed. I picked it up and placed it in its spot. The puzzle was complete. We walked around the hospital and snow began to fall around us. I stopped and gave my mom a hug, “are you okay?”
"You know, I think I am going to be alright. God is using the snow to tell us that"

died with everyone person that was dear to her standing beside her, helping her.

when dad died that the only thing she wanted was to not die alone. And she didn't. She

she is heaven. "She said as she raised her hand to catch a snowflake. "Grandma told me

\[
\text{XVI}
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Hi there.

Mourning Personified...

Stray against the bully.

It feels like walking through school hallways waiting for the bully to call me out then imagine your body and emotional strength. That's what being at your funeral feels like, just waiting for something to grab you and destroy me in front of all these people, some having already been picked on by that very bully.

Pipes slung over my shoulder my eyes sprint around the church avoiding contact with the hundreds of eyes, in front of me, all on me. Bully's feed on eye contact. Doesn't fit... a statement; role then I connect to my bro bro's (slang, use brother) and I am charged upon. He stumps, clenches fisted and glaring, describe more straight at me with every intention to end me to pin my shoulders to the ground and grind his calloused thumbs into my eyes to choke me shatter my throat shut and beat my head & body until they throb until they throb & (fail)

just as i feel his fingers reach to grasp my body i punch the bag and my pipes screaming and he stops, defeated for now and turns to the crowd and the tune of everyone standing tunnels into the heads
they were bold in my rearview mirror, 
a mother and daughter moving only their
wrists to put their cigarettes in their lips,
release the cigarette as they draw in smoke
and flick their wrists away as they exhale
through opened windows, looking skinny and
trampy, sexy and rich.

Do their clothes shrink?

Go ahead smell it as a kid, but it changes
your shirt and jacket I wore to some red curtains.

Do they cough every morning until they puke?

my father preachers this body at dawn. I can't sleep
through the progression of whooping coughs gaining higher
and higher pitch to the abdomen forced wretch clearing
the swampy liquid from stomach to lungs to throat to mouth
and finally to the sink where it lands with a mushy
slap and flow, congealed into the drain.
Precis

Research Hypothesis

Narrative medicine encompasses the practice of physicians, medical students, and other medical professionals writing about the stories of their patients' illnesses. The process of writing helps to humanize disease, medicine, and the physical body; specifically, narrative writing and familiarization with literature by physicians, other medical professionals, and students can create better-rounded, empathetic patient care. Narrative medicine courses are currently being developed in medical schools to create better-rounded physicians and to improve patient care by giving doctors better listening and communication skills, an understanding of the patient experience, and a more genuine realization and acceptance of their own emotions toward their patients. Currently, medical schools across the country are developing curriculum that focuses on literature and narrative medicine. Narrative medicine courses tend to contain three realms: 1) reading classical literature to understand social issues and the place of doctors in society, 2) reading patient narrative to better understand the patient experience, and 3) writing medical narratives about patients.¹

Context

Medicine has become increasingly immersed in increasing technology, proliferating insurance regulations, complicated administration and bureaucracy, and extensive specialization and sub-specialization. Many in the medical field believe that patient care and doctor-patient relationships have suffered as a direct result. The emerging practice of narrative medicine is meant to teach medical students and physicians to facilitate dialogue and genuine relationships with their patients, and

¹ See Figure 1, appendix.
Put your fucking wig on, please!

The sun in the morning is supposed to glisten off the dew in the grass and the trees like a million half-karat diamond engagement rings promising us, for that day, that it will be there to show us everything it can. I hate it this morning for choosing to turn its attention to the thousands of tiny hairs pricking up from my mom’s head. I have never seen her without a wig and as forged and obvious as they look they are necessary. Blind people put on sunglasses, fat people wear baggy clothes, rich people change channels on starving children, homeless people stay under bridges and dying people wear wigs. It is how it has to be so we can protect the rest of us from being uncomfortable. We know what’s really going on, sure, but we don’t want to be near it, to touch it, to smell it, to fully understand it because that means we, I, you are only human and that is not enough.

Doesn’t she know that it’s gross?

If I come out my room now I will explode. I will die. I will cry. Something bad will happen if I look her in the face and see how skinny and vulnerable she looks. Nothing else is out of the ordinary. It’s Sunday. I heard her start the coffee pot. Her mother called and they talked in the living about things I could not hear; probably about her brother and her father and Alex and I and Dad and how her treatments are going. Now the spinning wheel is clicking, twisting the hair of a sheep or a llama into yarn. The clicking the spinning wheel makes is different than the clicking of her knitting needles. The wheel clicking has a hum behind it, whirring and throbbing in intervals tuned to her pedaling. Occasionally she will stop because the yarn on the bobbin is tangled. The clicking and humming will stop and then start again, slowly as she gains momentum with
Why is she doing this? Why doesn't she have it on?

There will be sheep hairs in our toothbrushes and on our clothes and blankets. There is always animal hair everywhere; from an alpaca, a camel, a sheep, a llama, and from our Old English sheepdogs. It has been a long time since it has been a hair from her. I remember it being there and then it was gone. No discussion of hair loss, at least not in front of Alex or me. At least not me, but Alex is 5 years younger, so definitely not in front of him. She had two wigs; one was blue and kind of rock stakesque. Her serious wig was stylish like her real hair never had been. It was short in back and a little longer in the front where it swooped to the left. If her hair had not come back in so curly later on it would have been a good hair style to repeat. No one would know she were better because her hair would look like the old wig, but it would have looked good. The rest of the time, leisure times, she wore large rimmed baseball hats over a bandana. At least five different colors she had could be coordinated with her shifting, shrinking wardrobe. Even with the wigs and hats we knew, everyone could tell, that there was something ugly there, but these shrouded its face.

What is she doing this to me for?

If I go to sleep and I wake up later, by then she will have prepared herself to face the world and not stand out. I could sleep all day and tomorrow will be better. But I can't sleep and no amount of blankets over my head can stop the reflection of that sun off the pedal.
those hairs from burning into my head. It’s like trying to sleep on a runway with those lights in my head and every plane that lands and takes off are full of people leaving something behind and all of them judge me and hate me because my mom looks weird and makes them sad.
It was our last family trip.
I did not know it then.
My family and friends knew it.
I think the man selling pineapples on the roadside knew, too.
Because he gave one to us, no charge.
At breakfast we cut it into rings and ate it for the first time. It tasted good.
But not until the party after the funeral when I bit that tart cube from the end of the toothpick and, for the second time, ate pineapple.
When my mom took the one potato
of four that had exploded in the oven—it

was just like when she gave up her pilot career
to raise me,

was just like when she waived her life
so my brother could have his,

was unlike me not speaking at her funeral
and sharing these things,

so the other night I took the one piece of chicken
that was a little burnt.
The permanence hit me the hardest.
it demolished my brain daily
and wetted my face as I kept it low and
behind my hat brim.
I spat out my swallowed tears and tried
not to think
about you not being there for my
graduation
or my wedding
or to hold my first born.
All these thoughts were mixed with the
headaches from holding back too many
tears.
I just wanted to be tough.

But I grew from all of this,
I grew beyond what I should have been
at that age.
Understanding matured inside me,
understanding about being a human and
how other people choose to be humans.
I saw inside people, close people.
It's easy to do when the emotions run
rampant;
people didn't hide anything anymore,
they are too scared.

Some were scared like me,
of the permanence,
and they needed not say anything but
hold me and cry and laugh with me.
Treat me like a deserving human.
Then there were those who felt no
permanence,
only a sense of duty to spout off generic
answers in a deceitful tone about
a better place
and spirits and angels
and higher powers who needed you more
than we did
and I wanted to show them the pieces of
brain in my head that were in the
thousands,
no longer connected or certain of
anything,
and ask them why I didn't need you
anymore.
But I learned,
their consoling was merely selfish
and their fear only self-generated based
on a book and a theory.

I learned what kind of person I have to
be,
for myself and for my true friends who
showed me no mercy,
for mercy is not a cure,
but who showed me that life would
continue
and struggled and fought for us,
and I likewise fought for them,
to fill your gap,
gaping as it was for you are huge in
everyone who knew you.
I have pure friends.
And my brain is together again,
but I still miss everything that was.
The permanence still gets me,
but I understand now
and I thank you.