

## CLINICAL PRACTICE

# Exploring the patient experience of chronic illness through literature and film

Mariann M. Harding\*

School of Nursing, Kent State University Tuscarawas, New Philadelphia, Ohio, United States

**Received:** July 7, 2017

**Accepted:** August 22, 2017

**Online Published:** September 3, 2017

**DOI:** 10.5430/jnep.v8n1p54

**URL:** <https://doi.org/10.5430/jnep.v8n1p54>

### ABSTRACT

**Objective:** Caring for patients with a chronic illness requires a holistic approach. To help RN-BSN nursing students in a course focusing on chronic illness see the patient as a unique individual and to foster empathy by emphasizing the person behind each patient, literature and film were used to make the patient's lived experience of chronic illness real.

**Methods:** Students read autobiographies or biographies and viewed film about the patient experience of chronic illness. Materials were selected based on the illness and patient issues described. Using the Socratic Seminar, students prepared questions based on weekly reading assignments; faculty prepared questions for each film, encouraging active participation and group discussion of underlying insights. Many discussions revolved around select film scenes or quotations students selected from the text and the comparison to their practice experience with similar patients in the clinical setting.

**Results:** Satisfaction with the course was overwhelming, with all students rating every evaluative category as a "5", strongly agreeing that the course advanced their empathy towards patients with chronic illness. Comments detailed students' having a better understanding of how chronic illness truly affects the patient and family. The books resonated with the class more than the films, as the books had more detail and put the reader into the setting as if they were the person.

**Conclusions:** The use of literature and film is an effective means to enhance RN-BSN nursing students' ability to understand and empathize with a patient's needs and was successful in helping students understand the patient experience.

**Key Words:** Teaching strategies, Chronic illness, Pedagogy, Patient experience, Cinema, Film, Nursing education

## 1. INTRODUCTION

Nearly half of all adults, or 117 million Americans, are now living with a chronic illness, with as many as 29 million having more than 2 illnesses.<sup>[1]</sup> Chronic illnesses, ranging from Alzheimer's Disease to cancer, are the primary cause of death in the United States and care of patients with chronic illnesses accounts for most health care costs.<sup>[2]</sup> Having a chronic illness affects almost every aspect of a person's life, including life decisions, family, and work, requiring a holistic care approach to promote quality of life.

The health care system has been slow to move away from its'

focus on acute conditions. Even when a person has a chronic illness, the health care team often focuses on the acute intervention phase when the person presents as ill. For example, emphasis is placed on the nursing care of a patient with an acute exacerbation of chronic pulmonary disease who needs acute intervention for 2-3 days. With most chronic illnesses, adhering to a medication regimen and making lifestyle modifications is necessary to optimize health. Post-discharge, it is assumed the patient and caregiver will continue all the interventions needed and make any necessary modifications, whether the interventions are doable for them or not.

\*Correspondence: Mariann M. Harding; Email: mhardi10@kent.edu; Address: School of Nursing, Kent State University Tuscarawas, New Philadelphia, Ohio, 44663, United States.

Inherent in patient-centered care is the need to appreciate the whole person and to understand the person's specific needs and concerns.<sup>[3]</sup> An emotional detachment between a nurse and patient can occur when a nurse views the patient as simply the "patient with a diagnosis" rather than a unique person with a distinct illness experience.<sup>[4]</sup> Developing a holistic view of the patient requires moving beyond having technical knowledge to developing an appreciation of the significance of the chronic illness for the patient as they deal every day with managing daily life and grappling with their illness. Nurses need to appreciate how the patient is influenced by their life experiences, family, religious and cultural beliefs, and socioeconomic status.<sup>[5]</sup>

One way to make the patient experience more real and help nurses understand patient needs is by reading about or watch the "lived" experience of having a chronic illness. An essential element of using film and literature is that it enables others to view and apprise the situation from the patient perspective.<sup>[6]</sup> It helps to answer the basic question - what is it like to be a patient or the family member of a patient with a long-term illness or disability?

Using literature and film in nursing classrooms is not new, but has become a unique way of encouraging active learning.<sup>[7]</sup> Those who have studied their use report they can make an important addition to students' ways of knowing beyond factual content derived from textbooks or lectures.<sup>[8]</sup> Literature and film can be used help students gain a better understanding of concepts and theoretical perspectives, like stigma and suffering, that can be challenging to teach.<sup>[9]</sup> Their use can foster critical thinking. Everyone sees or reads the same thing but each person's impressions stimulate discussion on how the same content is interpreted differently.<sup>[10]</sup>

To help nursing students in an RN-BSN program see the person as a unique individual with his own understanding of the illness experience and to foster empathy by emphasizing the person behind each patient, literature and film have been used for three semesters as the pedagogical foundation in a course focusing on chronic illness. The ultimate goal was that through making the patients' lived experience of having a chronic illness real, students would be more empathetic and able to provide more competent, compassionate care to those with a chronic illness.

## 2. METHODS

Students were enrolled in a 3-credit hour course, Health Maintenance and Restoration for Professional Nursing Practice, at a regional campus of a large university in northeastern Ohio. The course is one of 9 required nursing courses in an RN-BSN program. The course is offered every semester,

with students meeting one day per week, for 5 hours, for 7 weeks, each semester. The pedagogy described here was utilized the past three semesters. Course objectives were to:

- Identify chronic illness and its impact on the person while promoting self-management and maximizing health
- Identify psychological and behavioral issues resulting from and impacting chronic health conditions
- Analyze the ethical and legal issues influencing the health and decision-making of people with chronic illnesses
- Analyze end-of-life concepts and assist the patient and family to achieve a peaceful death
- Recognize the importance of family members in managing chronic illness and rehabilitation

Students read autobiographies, biographies, and select fictional literature and viewed documentary film about the personal experiences of chronic conditions. Books and films were selected by the faculty based on the illness and types of issues described and their perceived worth in illustrating key concepts that would promote technical and ontological knowing (see Tables 1 and 2). Films were purchased from various retail Web sites for between \$2.00 and \$8.00 or viewed online if publicly available, and watched in class. Book assignments and the film watched each week purposefully represented similar concepts or conditions, such as the experiences of person who is quadriplegic, allowing for comparison of theoretical application.

Students were assigned readings from the textbook, *Chronic Illness: Impact and Intervention*.<sup>[11]</sup> The assignments introduced students to related theories and concepts, including loss, quality of life, social isolation, and powerlessness. Using the Socratic Seminar, students prepared open-ended questions based on weekly reading assignments while the faculty prepared handouts with discussion questions for each film. Other assignments included written reflections discussing their perspectives on the readings and class discussions and a paper detailing an interview of the lived experience of a person with a chronic illness.

Class was held in a comfortable, high-tech classroom. Each session opened with the seminar discussion of the week's reading assignment based on the students' questions, followed by a brief introduction to the film, including the year released, major actors, and any awards won. The film shown was related to at least one major concept or theory from the reading assignment. Students were given instructions to focus on certain scenes, such as "in the scene where the medical students are participating in rounds with the doctor, the patient says once I did the teaching, now I am taught".<sup>[12]</sup>

What does it mean to the patient to lose power? Films were shown without interruption with discussion following each film. Students were free to use the restroom. Most students

brought food and beverage and ate during the film. They appeared relaxed and were usually highly engaged during the entire class.

**Table 1.** Examples of literature with synopses

Book Title, Author, and Year Published	Illness	Key Concepts
Not Fade Away. Alexander R. (2015)	Biography of the experiences of Rebecca Alexander and her deteriorating vision and hearing from Usher Syndrome	Intimacy Resilience
Bed Number 10. Baier, S. (1989)	Autobiography of Susan Baier’s experience, particularly with the health care system, when left totally paralyzed with Guillain-Barré syndrome	Caregiving Powerlessness
The Diving Bell and the Butterfly. Bauby J. (1998)	Autobiography of Jean-Dominique Bauby, the editor of French Elle, who had locked-in syndrome after experiencing a stroke at age 43	Quality of Life Social Isolation
Blindsided: Lifting a Life Above Illness. Cohen R. (2005)	Autobiography by Richard Cohen, journalist and producer, who after having multiple sclerosis for 25 years, describes having two bouts of colon cancer	Quality of Life Uncertainty
Needles. Dominick A. (1999)	Autobiography of Andie Dominick’s life with type 1 diabetes mellitus	Adherence Self-Management
Tales from the Bed: On living, dying, and having it all. Estess J. (2005)	Autobiography of 6 years of the life of Jennifer Estess, her experience of having ALS, and her sisters and her founding Project ALS	Intimacy Social Isolation
Still Alice. Genova L. (2009)	A woman’s experience with having early-onset Alzheimer’s Disease	Powerlessness Stigma
Autobiography of a Face. Grealy L. (1995)	Autobiography of Lucy Grealey’s experience with Ewing’s Sarcoma, undergoing surgeries and chemotherapy, and being facially disfigured	Body Image Social Isolation
Too Late to Die Young. Johnson H. (2006)	Biography of Harriett Johnson and her life with a congenital neuromuscular disorder that left her unable to walk, bathe, or dress without aid	Quality of Life Resilience
Fractured, Not Broken. Weidenbenner M. (2015)	Biography of the experiences of Kelly Craig, who became quadriplegic after a motor vehicle accident involving a drunk driver	Intimacy Spirituality

A 12-item evaluation tool was developed based on two key themes: (a) Did the students believe they learned about caring for people with chronic illness from the books and films? (b) Did they come away with a new appreciation for the person’s lived experience of having a chronic illness? After each semester, students anonymously used the tool to evaluate their satisfaction with the course based on a 5-point Likert scale, ranging from 1, strongly disagree, to 5, strongly agree. Students could comment on each question and their overall experience. Evaluations from all three semesters course offerings were combined for this analysis.

### 3. RESULTS

A total of 32 students took the course over the three semesters. Satisfaction with the course has been overwhelming, with all 32 students rating every evaluative category as a “5”, strongly agreeing that the course advanced their empathy

towards patients with chronic illnesses (see Table 3).

Analysis of the students’ written comments demonstrated that the materials affected them in a powerful way. Students’ sentiments universally described their having developed a better understanding of how a chronic illness truly affects the person and family. Some of their comments include:

- “This course has encouraged me to make changes in my nursing profession in more ways than one. I now spend more time with families facing the end-of-life concepts and assist the patient and family to achieve a peaceful death.”
- “I have a different outlook when dealing with my patients, especially those with Alzheimer’s Disease and people who are battling disfigurement issues.”
- “From this class, I have taken many valuable lessons that have helped me to become a better nurse. The first

and most important was that it gave me the perspective of the patient and families dealing with a chronic illness and their limitations. Patients I take care of have many chronic illnesses and different kinds of support,

but I could never imagine what it is like for them on a day to day basis.”

- “I have learned a lot about caring for an individual with an illness rather than just caring for the illness.”

**Table 2.** Examples of documentaries and films with synopses

Film Title, Production Company, and Year Released	Illness	Key Concepts
Caregivers: The Alzheimer’s Project, HBO Films, (2009)	Documentary describing the caregiving experiences of 5 different families of persons with Alzheimer’s Dementia	Advocacy Caregiving
Hell and Back Again, Roast Beef Productions, (2011)	Documentary describing the physical and psychologic challenges of Marine Sgt. Nathan Harris, who was seriously wounded in Afghanistan	Pain Management Stigma
Indestructible, ALS Film Fund, (2008)	Documentary of 3 years of the life of Ben Byer, a playwright and actor, who sought to chronicle his life with ALS	End of Life Powerlessness
My Left Foot, Ferndale Films, (1989)	Based on the true story of Christy Brown, who overcomes cerebral palsy and having use of only his left foot to become an author and painter	Intimacy Quality of Life
My Life, Capella Films, (1993)	A man comes to terms with his terminal cancer diagnosis and the forthcoming birth of his first child	End of Life Spirituality
So Much, So Fast, West City Films, (2006)	Documentary of Stephen Haywood’s life with ALS, and his brother Jamie, who advocated for ALS research	Advocacy Intimacy
States of Grace, Open Studio Productions, (2014)	Documentary of the life of Dr. Grace Dammann, a physician left permanently disabled after a motor vehicle accident	Caregiving Resilience
The Sea Inside, Sogepaq, (2004)	Based on the life of Ramón Sampedro, who after becoming quadriplegic after a diving accident at age 26, fights for the right to end his life	Quality of Life Spirituality
Travis: A Soldier’s Story, Fotolanthropy, (2013)	Documentary of the life of Sgt. Nathan Harris, who became a quadruple amputee after being wounded in Afghanistan	Body Image Resilience
Wit, HBO Films, (2001)	A woman struggles terminal ovarian cancer, which gives her dramatic insight into the importance of kindness and compassion	Caregiving Powerlessness

**Table 3.** Course evaluation tool

<ol style="list-style-type: none"> <li>1. I can explain signs and symptoms of chronic illness.</li> <li>2. I can identify the concerns of those dealing with a chronic illness.</li> <li>3. I can explain the role of the caregiver and the emotions they experience.</li> <li>4. I can discuss the role of the health care system in caring for those with chronic illnesses.</li> <li>5. I can address the emotional needs of a person with a chronic illness.</li> <li>6. I can identify and explain barriers to a person adhering to therapy.</li> <li>7. I learned new ways to think about the illnesses and issues dealt with in this course.</li> <li>8. This course caused me to reconsider some of my former attitudes.</li> <li>9. I have learned the value of seeing the world through the person’s viewpoint.</li> <li>10. I have thought about the topics discussed in class outside the classroom.</li> <li>11. This course has advanced my empathy towards people with chronic illness.</li> <li>12. Using film and literature allowed for more effective learning than traditional textbooks.</li> </ol>
--

Overall, the books resonate with the class more than the films. Students enjoyed the detail from the “patients” in the books, feeling that they were put into the setting as if they were the person. Literature gave “a deeper look into how the patient felt about the diagnosis, how they coped with it, how the family coped, and how they perceived medical care.” Students indicated that the course content contributed

to their development as nurses, helped them to see different perspectives, motivated them to learn about new topics, and helped them reconsider their attitudes. It created an energetic atmosphere that was interactive, and “fun”, making students want to come to class. The discussions allowed for all students to actively participate and they liked the collegial atmosphere with their being able, as healthcare professionals,

to share their stories and discuss how to improve the patient care they provide.

#### 4. DISCUSSION

Using autobiographical, biographical, and select fictional literature and documentary film as the pedagogical foundation for a course focusing on chronic illness adds an element that goes beyond traditional studies, appearing to facilitate students becoming more empathetic and being better able to care for persons with a chronic illness. Using the Socratic Seminar as a pedagogy encouraged active participation and group discussion of insights into the person's lived experience, such as how did the person experience powerlessness or stigma? Most discussions revolved around specific film scenes or book passages that the students were able to compare to their experience with similar patients they had encountered in their practice. For example, in practice, students identified how they typically managed the care of those experiencing chronic pain. They were able to compare this to the needs of the person in the film or book, thus developing a better understanding of the influence of pain management on the experience of chronic pain. Having students develop questions allowed them to select those themes that most resonated with them. In several instances, passages and scenes that emotionally spoke to students were not ones that were selected by faculty. If students had not had a role in framing the class discussion, then those discussions may not have resonated with them thus diminishing the intent of the course.

Since several of the books and films involved persons at end-of-life, students discussed facilitating a "good death" and how to address ethical dilemmas that arise in providing end-of-life care. Tying together a book and film on the same concept or topic, such as the experiences of the dying person, allowed students to compare experiences, highlighting the uniqueness of a person's experience and helping students better understand what life is really like for persons with chronic conditions and their families.

Students reflected and subsequently questioned some of their routine nursing practice behaviors, compelling them to change practice behaviors in order to provide more patient-centered care. After watching *Wit*, several students remarked that they no longer entered the patient's room and routinely asked "how are you today", but instead asked patients questions, such as "tell me how your day went" or "what are your concerns while I am caring for you?" A few described being more cognizant of the words they used in conversation. Instead of "we need to suction you", they were specific in saying "I need to suction you." Similarly, many stopped using the word "okay" after stating to the patient care tasks that they needed to complete. They were equally critical of

depictions of caring behaviors, such as the lack of communication described by Sue Baier in *Bed Number Ten*, and how those depictions reinforced the importance of fundamental nursing care. One student descried:

"I work in an intensive care unit. I manage and care for a lot of ventilated patients who are sedated. This class has reminded me in a big way what I was taught the first semester in nursing school -to stop and explain each intervention and procedure that I'm doing before doing it and that the patient laying there is depending on me to care for them as a person."

The age of a few materials enabled students to look at various historical perspectives. In *Autobiography of a Face*, Grealey depicts how other youth treated her, describing multiple incidents of what today would be labelled bullying, and the lack of support from her family during chemotherapy.<sup>[13]</sup> Class discussion focused on comparing her experience in the 1980s to what students felt her experience might be today. At the time, the guidance counselor had Grealey eat her school lunch in the office each day to avoid taunting in the cafeteria. The students considered how Grealey's classmates would be held accountable today. Would she be less bullied at school? Grealey describes her family as being uninvolved in her care, with her mother reprimanding her when she cried. These depictions led to discussions of how nurses could encourage family to be more involved in-patient care.

There are several aspects faculty need to consider when using film and literature as a pedagogy. First, carefully select the films and literature. It may require time and effort to find the most appropriate materials that are congruent with course objectives. Then, consider the accessibility of the materials. Can a film only be shown in an educational setting or is it widely available? What are the film's copyright guidelines? Finally, what time is required for the assignments, both prior to and during class? How long is class? Discussion time may be limited depending on class length, particularly if a longer film is shown. Using film clips is a possibility and can allow faculty to highlight key concepts. However, an advantage to using an entire film is that students see the storyline and characters unfold over time.<sup>[14]</sup>

There are some limitations that may influence the applicability of this pedagogy to a broader audience. The findings described are based on a small, convenience sample of students at one university. Evaluation considered student ratings of pedagogical effectiveness, accompanied by anecdotal remarks; quantitative measurement of learning and empathy was not considered. It is difficult to know how the course

influences students' behaviors in the practice setting. Future studies could focus on developing assessment tools that are appropriate for the use of literature and film and quantitatively measuring changes in empathy.

## 5. CONCLUSION

The purpose of building a course based on literature and film was to foster empathy by emphasizing the person behind each patient. The use of literature and film appeared to be an

effective means to enhance students' ability to understand a patient's needs and was successful in helping students better understand the patient's lived experience of having a chronic illness. As a result, students developed a better sense of the holistic care they as nurses need to provide and felt they were able to provide more compassionate, patient-centered care to those with a chronic illness and their families.

## CONFLICTS OF INTEREST DISCLOSURE

The author declares that there is no conflict of interest.

## REFERENCES

- [1] Ward BW, Schiller JS, Goodman RA. Peer reviewed: Multiple chronic conditions among U.S. adults: A 2012 update. *Preventing Chronic Disease*. 2014. <https://doi.org/10.5888/pcd11.130389>
- [2] Chronic Diseases: The Leading Cause of Death and Disability in the United States. Available from: <https://www.cdc.gov/chronicdisease/overview/index.htm>
- [3] Plake KS. Book club elective to facilitate student learning of the patient experience with chronic disease. *American Journal of Pharmaceutical Education*. 2010; 74(3): 1-8. <https://doi.org/10.5688/aj740337>
- [4] Parker M, Smith M. Nurse-patient relationship theories. In M. Parker & M. Smith (Eds.), *Nursing theories and nursing practice*. Philadelphia, PA: F.A. Davis. 2015.
- [5] Northington L, Wilkerson R, Fisher W, et al. Enhancing nursing students' clinical experiences using aesthetics. *Journal of Professional Nursing*. 2005; 21(1): 66-71. PMID:15682163 <https://doi.org/10.1016/j.profnurs.2004.11.007>
- [6] Herrman JW. Using film clips to enhance nursing education. *Nurse Educator*. 2006; 31(6): 264-269. <https://doi.org/10.1097/0006223-200611000-00010>
- [7] Oh J, De Gagné JC, Kang J. A review of teaching-learning strategies to be used with film for prelicensure students. *Journal of Nursing Education*. 2013. <https://doi.org/10.3928/01484834-20130218-02>
- [8] Pohlman S. Reading Ella: Using literary patients to enhance nursing students' reflective thinking in the classroom. *International Journal of Nursing Education Scholarship*. 2013; 10(1): 283-291. PMID:24317789 <https://doi.org/10.1515/ijnes-2013-0013>
- [9] Oh J, Kang J, De Gagne JC. Learning concepts of cinemeducation: An integrative review. *Nurse Education Today*. 2012; 32(8): 914-919. PMID:22554554 <https://doi.org/10.1016/j.nedt.2012.03.021>
- [10] Masters JC. Hollywood in the classroom: Using feature films to teach. *Nurse Educator*. 2005; 30(3): 113-116. PMID:15900204 <https://doi.org/10.1097/00006223-200505000-00013>
- [11] Larsen PD. (Ed.). *Lubkin's Chronic Illness*. Burlington, MA: Jones & Bartlett Publishers; 2014.
- [12] Nichols M. (Director). *Wit* [Motion picture]. United States: HBO Films. 2001.
- [13] Grealy L. *Autobiography of a Face*. Boston, MA: Houghton Mifflin Harcourt. 1994.
- [14] DiBartolo MC, Seldomridge LA. Cinemeducation: Teaching end-of-life issues using feature films. *Journal of Gerontological Nursing*. 2009; 35(8): 30-36. PMID:19681561 <https://doi.org/10.3928/00989134-20090706-06>