Patients as Teachers, Medical Students as Filmmakers: The Video Slam, A Pilot Study

Dan Shapiro, PhD, Lynne Tomasa, PhD, and Nancy Alexander Koff, PhD

Abstract

In 2006–2007 and 2007–2008, the authors pilot-tested a filmmaking project, (medical students filmed patients) to assess the project’s potential to teach about the challenges of living with serious chronic illness. Two years of second-year medical students (N = 32) from The University of Arizona, working in groups of two or three, were paired with patients and filmed multiple home visits during eight months. Students edited their films to 7 to 10 minutes and added transitions, titles, and music. A mixed audience of students and faculty viewed the resulting 12 films in a “Video Slam.”

Faculty also used the films in the formal curriculum to illustrate teaching points related to chronic illness. Student filmmakers, on average, made 4.4 visits, collected 5.6 hours of film, and edited for 26.6 hours. Students reported that the project affected what they planned to cover in clinic visits, increased their plans to involve patients in care, enhanced their appreciation for patient-centered care, improved their knowledge of community resources, improved their understanding of allied health professionals’ roles, and taught them about patients’ innovative adaptations. Overall, students rated the project highly for its impact on their education (mean = 4.52 of 5). Student and faculty viewers of the films (N = 74) found the films compelling (mean = 4.95 of 5) and informative (mean = 4.93 of 5). The authors encountered the ethical dilemmas of deciding who controls the patients’ recorded stories and navigating between patient anonymity/confidentiality and allowing patients to use their stories to teach.


Surveys of practicing physicians in the United States and Canada have revealed that the majority of generalist practicing physicians feel their education did not prepare them to address the needs of chronically ill patients. In addition, medical students queried after clerkships report feeling frustration and sadness as a result of this work, and students’ desire to work with chronically ill patients diminishes with greater exposure during clerkships during which they report witnessing discrepancies between optimal and actual care delivery. In 2004, Pham and colleagues surveyed 16 representative medical schools and found that although course directors agreed that core competencies in chronic care are important, there was considerable variation in the degree to which the competencies were met and that, on average, two or more curricular methods were employed to address only 14 of 49 competencies. The authors concluded that more and better methods were needed.

Some have suggested that conventional course work and clerkship experiences for medical students may not provide students sufficient contact with patients to facilitate a deep appreciation for the challenges of chronic illness. With this in mind, a number of schools have created innovations that offer longitudinal exposure to patients. For example, creators of a pilot program at Harvard introduced an integrated clerkship in which students follow patients through the medical system for nine months rather than rotating through different clinics; in other institutions, faculty have changed how they manage clinics, or in some cases they have designed clinics especially for chronic care so that students might observe firsthand how patients with chronic illnesses might be optimally treated. Some schools have introduced programs centered on home visits. At Penn State Hershey College of Medicine, for example, Hunsaker Hawkins and colleagues created the Patient Project in which first-year medical students conduct home visits with the goal of enhancing their understanding of the psychosocial, spiritual, and financial aspects of disease. Similarly, at Weill Cornell Medical College, faculty initiated half-day home visits as part of primary care clerkships, and other schools both in the United States and abroad have followed suit. Still other programs have focused on building empathy for patients. At the University of California at Davis, faculty developed a simulation in which students participate in two days of workshops and lectures and are then assigned the task of performing self-care for two weeks as if they had a chronic illness. At Johns Hopkins, an elective rotation combines simulations, group discussions, and clinical experiences to increase awareness of biases regarding patients with chronic illness, to increase student insight, and to improve team communication.

Evaluation of these programs is usually through interviews, focus groups, or questionnaires. Initial results have provided some support that such programs can successfully teach students important approaches to working with chronically ill patients and, in some cases, can enhance empathy and positively affect trainees’ approaches to patient care.
Filmmaking as a Teaching Tool

Use of patient-made films to learn about patients’ lives

During the early 1990s, Mark Rich and colleagues, researchers at Boston Children’s Hospital, gave video cameras to children and adolescents with asthma and taught them to document their own lives. The approach was particularly effective at revealing environmental risk factors, medication adherence problems, and influential beliefs and behaviors. For example, 63% of the videos documented exposure to smoking that had been denied in clinical interviews. Rich and colleagues have subsequently analyzed the impact of creating videos on the lives of the patients, and early data indicate that making films improved these patients’ quality of life.

Innovation: Filmmaking to learn from patients about their lives

To the best of our knowledge, filmmaking has not previously been used as an interactive teaching tool for medical students. Filmmaking may have a number of educational advantages. First, using a camera requires active observation and listening. Filmmaking also requires editing, which is time-consuming and demands that students review the video they have shot in order to create meaningful narratives. In some cases, a filmmaker may watch the same clips 50 or 100 times while attempting to fix a transition or improve a sequence. This ongoing exposure and interactive learning may be an effective method for improving retention and expanding students’ knowledge base. In addition, the complexities of storytelling through film and its role in encouraging higher-order thinking have been explored by numerous filmmakers and theoreticians. (See, for example, the blog by Mathew Needleman, “Creating Lifelong Learners: Digital literacy, higher level thinking, and closing the digital divide”; available at: [http://www.opencourtreresources.com/ocr/blog]).

As a teaching tool for medical students, filmmaking may offer particular advantages. Many students find the idea of filmmaking attractive. It may also intensify the patient–student interaction for both students and patients because the patients are teaching not only the students directly in front of them over the course of the project but also, potentially, generations of students for years to come. Both the student filmmakers and the patients might feel pressure to be successful under the watchful eyes of other and future trainees. Further, we hypothesized that ongoing review of the material offered by patients would help students become expert at the issues presented in the films. Finally, short films, the end product of the project, may be easily integrated into the curriculum if they efficiently demonstrate key teaching points.

Ethical and moral concerns

As we began considering a project in which students would make films of patients and then show the films to not only one another but also, potentially, the larger health care community, we realized we would face a number of ethical issues. As most who work in clinical medicine are aware, patient privacy and confidentiality are now tightly regulated. Yet, from an ethical standpoint, confidentiality and privacy are not the holy grail of bioethics or morality. Patients have an autonomous right to decide how and when to disclose medical information. We suspected that some patients would be willing, if not eager, to share their stories in an effort to teach medical students.

A more complicated question concerned the degree to which patients should control the ultimate product of the films. The closest literature regarding the ethical issues of filmmaking in medicine can be found in the medical humanities, where a few scholars have examined the ethical and moral implications of using patient stories. Focusing on writing about patients, these authors have presented contrasting views. On one end of the spectrum, Rita Charon has insisted that patients should have the opportunity to review and reject the publication of anything written about them because they own their own stories. Citing potential damage to patients, including ongoing exposure to difficult events, embarrassment at having been revealed, or lowered self-esteem if the portrayals are unflattering or result in stigmatization, Dr. Charon argues that the patients’ legal power to control publication of their stories is necessary to protect them.

Others, including Coulehan and Hawkins, have argued that this guideline is unwieldy. If followed rigidly, no one could create narratives about patients who speak different languages, have left treatment, have died, or are seriously infirm. Because physicians often also write about themselves and disguise patients, the potential to damage disguised patients is minimal.

In a recent Atrium article, Tod Chambers, an ethicist, has argued for informed consent: Scholars should seek permission when they write patient narratives or conduct other scholarship that may compromise patient anonymity. Although this permission-seeking has been common in the social sciences for decades (the first author of this article is a psychologist), in the medical humanities the issue of who controls patient stories is only now being addressed.

From a bioethics perspective, the relevant principle is patient autonomy. Competent patients have the right to choose to opt in or out of a variety of treatments and educational programs. In many corners of medical education and medical practice, physicians or other medical personnel routinely explain what a patient is going to experience—as well as the risks and potential benefits—and allow patients to consent or refuse. Most dramatically, patients consent to donating their bodies for the anatomy portions of medical training and allow medical students and residents to perform painful and even dangerous procedures.

In our filmmaking project, we did not give patients the right to prevent the showing of films about them after the fact (i.e., after the students created the films) but decided to rely on the informed consent process to systematically discuss the risks of the project with patients. Although the project was exempted from full internal review board (IRB) review, we used the same consent process used in other clinical trials.

In addition to negotiating between the need for patient confidentiality and autonomy and the good of allowing patients to teach and tell their stories, we encountered an additional ethical issue. Filmmaking differs from writing in some...
important ways. Unlike writers, who control the entire narrative about a patient, filmmaking requires editing of patients’ verbalizations and actions. When filmmakers edit a patient narrative, they are choosing which of the patient statements and actions to include and which to discard. These discards can alter patient meaning. Unlike written essays, which are assumed to be the sole perspective of the author, editing film gives the editor the power to modify a patient’s own presentation through the inclusion or exclusion of relevant information voiced or performed by the patient him- or herself.

Because the goal of the project was to teach students by compelling them to spend significant time with the film through the editing process, giving control of the editing process to patients would have destroyed the project. (Further, there were no guarantees that patients would honor the truth more than the students.) We decided to institute a number of safeguards to optimize the chances that the resulting films would be accurate. The first author watched all of the recorded film and was able to compare the results with the edited versions. Second, we encouraged students to strive for precision and accuracy in their editing, and we repeatedly asked them via regular meetings to carefully consider the information they were editing out. Finally, we reminded students that the patients would be invited to the Video Slam presentations and given copies of the films.

The Filmmaking Project
Initial administrative reticence
Administrators were initially reluctant to support and allow the project for two reasons. The project seemed to require both a dramatic outlay of faculty time and substantial financial resources for equipment. The potential benefits of filmmaking as a teaching tool seemed initially to offer only a vague payoff. To address these concerns, the lead author conducted the project as if he were a student and filmed a family member with lung cancer for one year (with her consent). He then edited the film and showed it to the administrators. The film documented how the patient felt about the medical personnel who treated her; her struggles with adherence; and the profound impact her illness had on her mother, husband, and grandchildren. After viewing the film, administrators indicated they felt they had a better understanding of the scope of the project and the potential teachable moments it could generate, so they approved the project as a small pilot.

Preparing to conduct the project
Two sets of second-year medical students from the University of Arizona who volunteered for approximately eight months participated in the pilot project. Thirty-two students were recruited through mass e-mails to the medical student listservs. We recruited 10 students for the first year (2006) and planned on 16 for the second year (2007), but ultimately, 22 students (20.4% of the class) asked to participate in the second. Students ranged in age from 22 to 30; 18 female and 14 male student filmmakers participated. Most students had no filmmaking experience, and roughly two thirds had not done any significant video-taping. Twenty percent self-described themselves as having had moderate filmmaking experience, and two students had significant (self-described) experience editing and working with cameras. Four students did not complete the project. In the first year, one of the patients dropped out, precluding two students from finishing the project, and in the second year two students took an opportunity to study abroad during their second semester. In both cases the resulting film was erased.

Students received two orientations. In the first (two hours), they learned to use high-end (not high-definition) consumer digital video camcorders (Panasonic PV-GS500, Secaucus, NJ), audio microphones (Azden WR- / WM-Pro, New York, NY), and tripods. They practiced taping one another and learned basic information about lighting, audio, and framing a shot. In addition, they also learned that films can be constructed of video that has good audio, good video, or both. Capturing great images, even if they have bad or no audio, can serve as “B-roll,” which can help in creating compelling film (B-roll is extra video footage intercut with the main shot and is typically used to enhance the visual experience). The second orientation (one hour) focused on the requirements of the project. We asked students to organize themselves into groups of two or three.

We explained that the project’s requirements were minimal in that the students needed to make only three visits, including one medical visit; however, we encouraged students to “throw [them]selves into [their] patient’s lives” and to feel free to improvise and follow their curiosity. We told them to ask questions and to “video-tape everything you can think of including what’s on the refrigerator, pets, and favorite activities.” We reminded students that accuracy was important, and we advised them that their films would be strongest if they truly captured the patient’s life.

The IRB of the University of Arizona exempted this project from full review, but, as mentioned previously, we chose to use consent forms anyway. These were identical to the ones typically used in clinical trials. As an extra precaution, we had them vetted by university attorneys. One form was designed for the patient and family members. It fully explained the project, the process the students would go through to make the films, and the risks and benefits of the project, especially giving up confidentiality. We designed the second consent form, a “one sheet,” to be completed by anyone who appeared on camera who might reasonably expect privacy. (The reasonable expectation of privacy is a legal definition, referring to where taping occurs. If people stroll in a public park, they can legally be filmed without consent. If they are at home, they cannot legally be filmed without consent.)

Early issues in the procedure
After we gained approval for the project, we had early concerns that participating medical students might feel pressure to “know something useful” to give back to the patients. We wanted to avoid a circumstance in which students might share their limited knowledge with patients in an effort to repay patients for their time. To address this issue, we reminded students “to be students.” We recruited the patients for this project to teach our medical students and, in so doing, to assume a position of authority. In initial discussions with potential participants, we stated the following: “You are the expert at coping with _______. You understand its struggles and the day-to-day challenges far better than our students. We are asking you to share your expertise with our medical students who probably know very little about
living with ______." We also reminded our patients that our students were nearly at the beginning of their training and could not offer medical opinions. In combination, these interventions seemed to reduce the pressure the medical students felt to have expertise. Notably, the patients (or, in some cases, their parents) in the project quickly assumed the position of authority, offering their expertise as teachers in the same ways a professor might. As a result, we began to use the phrase “patient–teachers” to describe their role.

Some faculty also wondered whether students would feel awkward entering patients’ homes. Fearing problems, the first author accompanied the first groups of students on their initial home visits. It was quickly apparent that although the visits were a little awkward for everyone, the presence of faculty did not diminish this and the students were fully capable of navigating visits alone. Students later indicated that the awkwardness of the initial visits was no different than the newness of being introduced to clinical medicine and that, in some ways, because little clinical expertise was expected, they felt less pressure. It is also notable that many faculty, trained in hospitals and clinics, had no more experience doing home visits than the students.

Participants: Patient–teachers

We were surprised at the ease of recruiting patients for the project. The most common reason patients gave for wanting to participate was “I’d like others to benefit” and/or some variation of “I think young doctors could do a better job.” Often, patients were less interested in privacy and confidentiality than they were in teaching and sharing their expertise. In addition, some referring physicians indicated they felt the exposure to medical students might be helpful to isolated patients. Rather than seeing the project as a benefit for students, these physicians felt it might be helpful for some patients to have someone visit with and listen to them.

In two cases, as a result of the screening process that focused on the potential loss of confidentiality and on the requirement of allowing students into one’s home, the first author convinced potential participants not to do the project. In one of those cases, a young man with HIV was asked not to participate because his parents did not know of his HIV status. Though his parents resided outside of the local area and the patient felt his participation could help students understand his disease, the first author explained that the films’ potential reach could extend beyond the local area. In another case, the patient’s children were unaware of his/her neurological condition, and this patient made the same decision not to participate.

Patient–teachers in the first year included a woman with metastatic breast cancer, a young man with AIDS (who was “out” to his community and family), a family with two children with juvenile-onset diabetes, a woman who had suffered a head injury after a motor vehicle accident in which her daughter was killed, and a woman with advanced lung disease. After two months, the patient–teacher with advanced lung disease declined future participation and dropped out of the project because she did not want to be filmed when she was not “looking her best.” In that case, the film was erased. Students from the other four teams made between three and six home visits and followed the patients to medical visits. In addition to attending home visits, some of the filmmakers also decided to attend and film other activities including a bone marrow transplant reunion, a birthday party, and restaurant outings. In one case, the student filmmakers accompanied and filmed a patient who struggled with ambulation as she traveled from her home by bus to her place of work.

In year two, participants comprised four pediatric patients, two young adult patients, and three older adult patients. The pediatric patients included a six-year-old with alveolar rhabdomyosarcoma requiring amputation, a child with cystic fibrosis and trisomy 21, an infant with congenital anomalies requiring lifelong ventilation and a tracheotomy, and a young boy with severe hemophilia A. The young adults included a 22-year-old man with recent-onset paranoid schizophrenia and a 27-year-old with Duchenne muscular dystrophy. The older adults included a woman with lifelong arthritis, a woman with Parkinson disease, and a woman with blindness and a history of breast cancer. None of the patient–teachers dropped out the second year.

Time spent in the project and project requirements

We required students to visit the patients three times, including one medical visit. The mean number of visits was 4.42 (SD = 0.38), and the range was 3 to 10. (The group working with the young man recently diagnosed with paranoid schizophrenia met with him and his family five times before ever filming.) Students generated 5.56 hours of film on average (SD = 1.27), with a range of 3 to 8 hours. Editing was particularly time-consuming. Cutting a film from more than 5 hours to between 7 and 10 minutes requires careful thought and experimentation. The mean number of hours of editing was 26.63 (SD = 29.86) but ranged from 6 to 120 hours.

The requirement that each team follow a patient on a medical visit from start to finish was important to the project. Although the majority of the teams met this requirement, three groups did not, either because the patient had no appointments scheduled during the eight months or because the medical professional involved declined to appear on film. In two cases, the students attended the medical visit but did not film it. Some students wrote that they observed a dramatic difference between how their patient behaved at home and how he or she behaved at the office with physicians. Some students also reported being surprised by the relatively low amount of information that medical personnel and patients exchanged during the visits compared with the amount of information available. In addition to meeting with physicians, students in some groups also attended chemotherapy treatments, allied health professional visits, etc.

Mentorship

During the filming process, every group met with the first author at least once to discuss filming. A few groups met more frequently as they faced hurdles including scheduling time with patients and dealing with sensitive topics. In the second year of the project, the team working with a young man recently diagnosed with paranoid schizophrenia struggled with how to raise the issue of his diagnosis with him. The total count of these contacts between faculty and students is unknown because the first author frequently met informally with the teams.
after lectures. After filmmaking was complete, the first author met with every team three times: first, to explain the logistics of the editing process and to ask the students to cut their hours of film down to a first cut of 25 minutes; the second time, to review the 25 minutes of initial content and to discuss further trimming; and finally to assist the students in their final editing attempts. Each of these meetings lasted at least one hour; some lasted as long as 2.5 hours.

Students were not evaluated in the project, and no credit was offered. The project was entirely voluntary.

The video slam
The films (available on request; please contact the corresponding author) were shown in two venues: first as part of a “Video Slam”—advertised through listserv announcements—open to the larger academic health sciences community, including students and faculty, and as part of a two-hour session focused on chronic illness during a lifecycle block in the second year of the curriculum. In the first year, we did not track attendees at the Video Slam, nor did we use any inventories to capture audience response to the films. In the second year, 145 audience members viewed the films, and of those, 74 stayed after the films to complete brief inventories. Student and faculty viewers found the films both compelling and informative (mean = 4.95 out of 5) and informative (mean = 4.93 out of 5).

Evaluating the Filmmaking Project
The evaluation was conducted using a questionnaire that had 33 questions including

- seven questions (measured on a five-point, Likert-like scale) measuring the students’ global ratings of and views on the clinical relevance of the project
- five open-ended questions such as “What was the most difficult or challenging part of this project?”
- three questions focused on logistical issues such as the number of visits the project required (discussed above),
- nine questions (measured on a five-point, Likert-like scale) focused on the degree to which the project helped students meet specific learning objectives such as “understanding psychological processes patients go through,”
- seven questions (measured on a five-point, Likert-like scale) that covered the content that emerged during the visits such as adherence, and
- two yes/no questions asking whether the project should be experienced by more students and whether it ought to be a requirement.

Clinical relevance and global ratings of the project, as viewed by filmmaking medical students
As other researchers have observed, medical educators are fully capable of producing novel educational offerings that satisfy students. More important, perhaps, are the specific learning objectives such offerings address. At the end of the filmmaking project, we asked students questions about the degree to which the project impacted their clinical thinking and a global question about the influence of the project on their medical education. Three questions and the students’ mean ratings are as follows:

- After this project how likely are you to involve patients in directing their own care? (1 = less likely, 5 = more likely) (mean = 4.3, SE = 0.05);
- To what degree did the visits and the creation of the video impact your thinking about what should or should not be covered in a clinic visit? (1 = no impact, 5 = significant impact) (mean = 4, SE = 0.17); and
- How much of an impact did this exercise have on your medical education? (1 = no impact, 5 = significant impact) (mean = 4.52, SE = 0.13).

Project challenges and impact, according to student filmmakers
Open-ended questions asked students to describe the impact of the project, its challenges, and its impact on their view of patients with chronic illness.

Interestingly, editing was listed by different teams as one of the most enjoyable, but most difficult, parts of the project. In a few cases, the students encountered frustrating technical problems. One group taped a patient’s interview with and physical exam by a nurse practitioner, but the students did not remember to attach the audio receiver to the camera and had no sound in the final tape. One tape was lost, requiring students to retape an interview. A few groups had problems with the software when their files grew larger than the software could adequately handle. Finally, other difficulties included scheduling time to meet with health professionals, keeping patients on-task during interviews, and no longer being a part of the patient’s life at the end of the project.

Two student groups, one each year, also had conflicts between filmmaking partners. In both cases, the teams seemed to be constructed of strong-willed, successful students who had different ideas about how editing should proceed. In both cases, one of the filmmakers dropped out during the editing process out of frustration. Meetings with the project mentor, the first author, were not successful in reengaging the frustrated students.

Despite these difficulties, the vast majority of students wrote enthusiastic responses:

I learned that caring for a chronically ill person not only means caring for the patient but instead means caring for the entire family. And I think that sometimes physicians forget that the family is who cares for the patients and in most instances knows the patients best. As physicians we have to listen and take into account what the family says because they usually know what’s going on much better than we could ever imagine. In our case [the patient’s] mom was basically a self-taught nurse!

I felt that the benefit of this project was twofold. First, it exposed me to all the factors of chronically ill patients … financial strain, family roles, patient/physician relationship, etc. Second, it showed me, in a very intimate setting, how a family responds to tremendous stress, grief, and fear, and the strength, hope, courage, and incredible outlook on life that are brought about by such a situation. It was remarkable and inspiring and speaks volumes to the importance of considering the patient as a human being as opposed to a medical chart.

Specific learning objectives and aspects of care
We asked students which learning objectives the project covered. As Table 1
Table 1

Students’ (N = 27) Assessments of Which Topics Their Films Covered*

<table>
<thead>
<tr>
<th>Issue</th>
<th>Mean (standard error)</th>
</tr>
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<tbody>
<tr>
<td>Personal relationship issues</td>
<td>4.04 (0.24)</td>
</tr>
<tr>
<td>Impact of the illness on family or friends</td>
<td>3.95 (0.26)</td>
</tr>
<tr>
<td>Environmental challenges brought on by the chronic illness/disability</td>
<td>3.86 (0.25)</td>
</tr>
<tr>
<td>Accessing community resources</td>
<td>3.73 (0.25)</td>
</tr>
<tr>
<td>Accessibility of physician</td>
<td>3.63 (0.20)</td>
</tr>
<tr>
<td>Misconceptions or prejudices toward individuals with chronic illness or disability</td>
<td>3.39 (0.30)</td>
</tr>
<tr>
<td>Adherence issues</td>
<td>2.79 (0.34)</td>
</tr>
</tbody>
</table>

* The students used a five-point scale where 1 = Not at all and 5 = Very much. All items are significantly greater than 1 in a single-tailed t test at .05. Not all of the participating students completed questionnaires.

during filming. For example, one film recorded the following interaction between a woman with metastatic breast cancer and the student filmmakers, whom she had invited into her kitchen to teach them about her medications:

[Patient pulls basket, full of medications, from kitchen cabinet.]

Patient: This is everything I take every day except my eye drops.

Student: How do you keep track of it all?

Patient: I know, that’s what I’m telling you.

Student: Yeah.

Patient: Yesterday I was feeling so tired and I told my husband and then I realized, I forgot to take my Potassium.

The student filmmakers included this scene in the final film. Despite this, the student completing the questionnaire (who put her name on her inventory) indicated that adherence had not come up during the project. Perhaps students’ loyalty to their patient–teachers impacted their willingness to endorse that item, or perhaps the definition of adherence was not clear to the students. Other films showed that patients struggled with following through on appointments, adhering to medication regimens that required the vigilance of other people (teachers, for example), or complying with an extremely complex regimen, as in the case of the young man with AIDS.

We asked student filmmakers the degree to which the Video Slam project helped them understand various aspects of care. Table 2 presents those ratings. Students indicated that the most salient patient-care issues they learned about included the impact of the illness on the patient and patients’ psychological issues.

**Community resources.** We also asked students, both before and after the project, about their knowledge of how community resources assist, or fail to assist, patients and their families. Their knowledge before and after was significantly different. The mean before rating was: 2.125 (SE 0.90) (where 1 = no knowledge and 5 = a great deal of knowledge). The mean after was 4.08 (SD 0.51); t = 10.05, P < .0001.

**Knowledge of allied health providers.** Students’ knowledge of the roles and responsibilities of various health care providers was also improved from before the filmmaking project (mean = 2.54, SE = 0.69) to after (mean = 3.83, SE = 0.40); t = 7.37, P < .0001. In the course of making the films, many of the students had opportunities to watch and film allied health professionals including physical therapists, psychologists, nurses, case workers, pharmacists, occupational therapists, and techs.

**Witnessing and transmitting patients’ innovative adaptations.** Many of the students had opportunities to witness and film patients’ innovative approaches to managing their illnesses. In many cases, the students chose to include these innovations in the final films. For example, one film recorded a mother who had to remove her child’s tracheotomy every day to suction the toddler’s throat. She developed a routine in which she sang “The wheels on the bus” while changing the connection from the ventilator to his tracheotomy so that he would have a sense of how long he was going to have to wait while air hungry (less than one complete, quickly sung verse). Another film showed a mother bouncing her adult son back on his bed so that he would spring upward, which allowed her to get a good grip beneath him. This facilitated his transfer from bed to wheelchair. In a third film, a mother expressed how she cajoled her six-year-old into taking insulin shots by allowing him to give her saline shots first. “I never chased him with a syringe,” she says; “I didn’t want my child to have memories of his mother chasing him with a syringe.” The data reflect this opportunity to witness these innovations. Table 2 shows that when asked the degree
Students’ inventories contained some adaptations and resilience. Most of the students’ impressions of their patients’ psychological responses to illness. Open-ended questions revealed the patients’ adaptability and triumphs.

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Table 2
Students’ Ratings of What They Learned From the Filmmaking Project From 1 (Strongly Disagree) to 5 (Strongly Agree)

<table>
<thead>
<tr>
<th>The video slam helped me to...</th>
<th>Mean (standard error)</th>
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<tr>
<td>. . . understand the impact of symptoms and side effects on patient functioning and well-being.</td>
<td>4.46 (0.13)</td>
</tr>
<tr>
<td>. . . understand the psychological process patients go through when adjusting to a chronic illness or disability.</td>
<td>4.46 (0.15)</td>
</tr>
<tr>
<td>. . . understand the innovative adaptations patients generate to cope with ailments and disability.</td>
<td>4.42 (0.15)</td>
</tr>
<tr>
<td>. . . understand the difference between patient-centered versus health-professional-centered (physician) health care.</td>
<td>4.36 (0.13)</td>
</tr>
<tr>
<td>. . . understand the impact a chronic or serious illness has on other family members and friends.</td>
<td>4.33 (0.21)</td>
</tr>
<tr>
<td>. . . understand the challenges for the patient in adhering to a medical regimen.</td>
<td>4.33 (0.15)</td>
</tr>
<tr>
<td>. . . understand the challenges for the family when the patient must adhere to a medical regimen.</td>
<td>3.82 (0.28)</td>
</tr>
<tr>
<td>. . . understand the financial burdens associated with caring for a patient with a chronic illness or disability.</td>
<td>3.71 (0.25)</td>
</tr>
<tr>
<td>. . . understand the insurance issues associated with care.</td>
<td>3.58 (0.23)</td>
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Psychological responses to illness. As noted in Table 2, students indicated that the filmmaking project helped them to understand patients’ psychological responses to illness (mean = 4.46, SE = 0.15). The mode and median were both 5 out of 5. A few of the patient–educators refused to talk about their psychological responses to their illnesses, but the films themselves contain considerable psychological data:

- The patient–teacher with metastatic breast cancer said on film, “Some people are angry. And they think, ‘Why did this happen to me?’ But if you really stop and think about this, it shouldn’t happen to anybody [pause] and sometimes you do have to get angry, but then you know what! You have to get on with it. And I really think that helped me.”

- An older woman with arthritis said, “I get depressed sometimes and I try to face the depression head on. I have a little pity party, and then I [word omitted] it out. I just [word omitted] it out.”

- The father of a young man recently diagnosed with a severe mental illness noted, “Schizophrenia is a disease that happens to the entire family. I don’t think I’ve been happy for more than a year.”

- A woman caring for her son with muscular dystrophy said, “I don’t want to go to a support group or talk to a professional. They haven’t been through it. I want to talk to other mothers who’ve been through it.”

Other patient–educators discussed loneliness, the psychological impact of being homebound, the challenges of explaining a biopsy to a child going through chemotherapy, being truthful with children, managing psychological side effects of medications, and the impact on couples when one of the pair or their child is ill. Students appreciated the complexities of the patients’ responses. One student wrote, “The most valuable part for me was knowing how hard [the patient] tries to accomplish things and yet has resentment for her disease. That dichotomy is not brought forth in our studies. The patient is usually portrayed as a fighter or an invalid.”

The importance of home visits to learning about patients with chronic illness

Two final yes/no questions asked participating students whether they felt that more students should complete the project and whether the medical curriculum should require a chronic care experience including a home visit. One hundred percent of the student filmmakers indicated that yes, they felt more students should be involved. One hundred percent also felt a chronic care experience involving home visits should be required. Notably, in comments, many students indicated that they were not sure that a filmmaking project should be required.

A surprising ethical issue

In a number of cases, we were surprised that students sacrificed their the films’ accuracy to honor their patients’ autonomy. Patients frequently made candid statements to the students and then asked the students not to include the statement in the final film. For example, one patient complained bitterly about her physician’s bedside manner, eloquently listing the ways in which he could improve, and then said, “Don’t include that. I don’t want to get in trouble, and I don’t want you to get in trouble.” Although the statement would have been enormously educational for viewers of the films, this request and all like it were honored, even though the editing resulted in the final film being less, rather than more, accurate. In another film, a mother acknowledged allowing her child to inject her with insulin before she injected him. The mother’s act brilliantly illustrated her complex feelings of guilt for “not being the one who got diabetes.” Yet, it was also a dangerous activity, and the mother felt some embarrassment (she was admonished later by her child’s nurse). The students included the mother’s description of allowing her son to inject her with saline but granted the mother’s request to edit out the description of the insulin injection.
More commonly, patients requested edits for other reasons; in one case an older patient had a tendency toward profanity. Laughing, the patient suggested the film would be better if those words were not used. In other cases, patient–teachers just wanted a chance to repeat themselves more articulately, and all of these requests were honored. Although not formally assessed, the patients seemed to enjoy the edited, final films, and a number of families asked for additional copies to distribute to friends and family. Still, the students and the faculty have remained somewhat uncomfortable when students sacrificed accuracy in favor of patient control.

Limitations
The evaluation of this pilot project has a number of limitations. First, there was no control group, no long-term follow-up with the students, no pre–post evaluation of the students, and, like many educational innovations, much of the evaluation relies on self-reported data from questionnaires, which are vulnerable to bias. In addition, the student participants were volunteers. The degree to which the enthusiasm, learning, and completion rates would diminish if the project were required is unclear, but all would likely decrease. Filmmaking may be attractive to a large enough number of students that the project might be an easier “sell” than many other requirements. On the other hand, the project does require a significant outlay of energy and time, and students who have no intention of working in specialties that require contact with patients with chronic ailments might justifiably balk. The minimal mastering of editing software, required for the success of the project, would likely also antagonize some students. In addition, the outcomes we measured are not robust. Questionnaire responses are informative, but they cannot tell us the degree to which this project truly impacts patient care or students’ behavior when they are working in clinical environments.

Funding
We made purchases for the project twice. The first time, we bought two cameras, two audio receivers, and two transmitters for the four groups of filmmakers. A laptop was available (at no additional expense) for editing. We also created a Google calendar (also at no additional expense) so that students could reserve equipment. The second year, we purchased two more cameras and two newer laptops for editing. Table 3 shows these and other expenses.

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Generalizability
This project is likely generalizable to other institutions. Teachers and investigators at Florida State College of Medicine, Thomas Jefferson University, Southern Illinois University, and the University of Hawaii have expressed interest, and Dr. Jeffrey Spike at Florida State has completed a modified version of the project with elderly patients. More than 100 medical educators nationally (and 8 internationally) have requested copies of the short films resulting from this project. The methodology employed in this pilot project may be useful for a variety of health professional trainees and practitioners in a number of circumstances. Although we used it as a tool for teaching about chronic ailments in this pilot study, we have no doubt that making (and watching) short films could also teach, for example, surgery residents about the long-term sequelae of various surgeries, emergency room trainees about the lives of patients who present to emergency departments, or allied health professionals about the long-term impact of physical therapy. Intraprofessionally, this may also be a valuable project to conduct with health professionals from different disciplines.

The time cost and viewing the films
Clearly, filmmaking is time-consuming. In an age in which time is a precious commodity, the manpower and financial costs of conducting a Video Slam are significant. Although the students in this project seemed to make specific gains in learning about how patients cope and struggle with the challenges of chronic illness, the degree to which institutions will be willing to invest the time into the logistics of such a project is unknown. However, were the project implemented widely, it would produce a collection of films documenting patient experiences that could efficiently teach health trainees a great deal about how patients live with long-term illnesses and their challenges. The long-term educational benefits of watching the films are unclear. Although short-term ratings of the films indicate that the audience strongly felt the films were valuable learning tools, the environment was subject to bias: the filmmakers were present, many in the audience were aware of the efforts of the filmmakers, and there was a packed house with an air of excitement and anticipation. Ratings from more common educational venues may temper the extremely high ratings. Future work will evaluate the utility of short films about patients’ lives as teaching tools.

Future work may also test the viability of the project as a requirement for medical students. Patient–teachers with other ailments and concerns will also be recruited. During the next round of the project, patients struggling with infertility, posttraumatic stress disorder, bipolar disorder, autism, seizure disorders, and Alzheimer disease are planned.

In Sum
This study provided initial evidence that students can learn about living with chronic illness through making short, compelling videos of expert patients. Student filmmakers reported learning about the impact of chronic illnesses on relationships, the psychological impact of chronic illnesses, the roles of allied health professionals, the availability (or lack thereof) of some community resources, and, to a lesser degree, about insurance challenges, adherence issues, and the financial impact of care. Students reported observing many of their patients’ innovative approaches to illnesses. In addition, as a result of working on the project, the majority reported changing what they hoped to cover in clinic visits and planned to increase the amount they involved patients in their own care.

We encountered a few surprising ethical dilemmas. When we proposed seeking consent from patients to record their stories, precluding confidentiality, it was initially opposed by administrators. Later, during the project a few of the patient participants articularly explained
Negative experiences they had experienced in the medical system with specific physicians and then later asked to edit those comments out of the final films. These negative comments would have been invaluable teaching tools. The bioethics principles at conflict in these cases were patient autonomy and truthfulness, and we erred, for better or worse, toward patient autonomy.

Notably, responses to our open-ended questions revealed considerably more optimism about patients with chronic illness than have prior surveys of students who have worked with patients only in conventional clerkships. Student filmmakers focused considerable energy on filming and conveying patients’ triumphs and adaptability and seemed eager to share this in the questionnaires and films. It is possible that when medical educators expose students only to patients in the midst of medical crises, students erroneously conclude that these crises are representative of the patients and their lives. Our students discovered other facets of their patients’ lives, and this may be why so many participants indicated they felt that a chronic care experience involving home visits should be required for all medical students.

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Disclaimer

The short films described in this project are not for sale. As of this writing, fewer than 100 have been distributed for free to a number of medical educators.

References