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## From the Instructor

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As with the best arguments, the idea for Lauren Kesler's essay came from a deeply personal place. An aspiring documentary filmmaker, she began with the simplest of questions: What documentary film needs to be made? Her answer—an autoethnographic film that gives ill children directorial power over their own representations—wonderfully synthesizes the academic and the public, the theoretical and the practical.

Lauren wrote this essay for our WR 150: “Global Documentary” seminar as part of the WR X Genre and Audience Cluster. Students researched documentary films that piqued their interest and then wrote on their topic in three different genres for different audiences: a research proposal, an academic research paper, and a public intellectual essay. Their topics spanned disciplines and the globe, from the decline of Chinese ethnic minorities to the rise of adjuncts in American universities.

There is so much to admire in Lauren's essay: its extensive research, logical organization, and overall originality. I particularly appreciate the gentle confidence and humor of her voice, even when working with a subject as tragic as this one. It is gratifying to see Lauren honored for her topnotch essay, which lays the groundwork for what will be a revolutionary documentary. I await an invitation to the premiere.

— Marisa Milanese

WR 150: Global Documentary

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## From the Writer

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I had often thought of making a documentary film about childhood illness in the traditional documentary format, with a film crew following and interviewing children. Eager to develop the project, I decided I would write my research paper for my WR 150 class “Documentary Film: A Global Perspective” as a proposal for this film.

As I began to research films like *Maidentrip* and *Born Into Brothels*, which both put cameras into the hands of the subjects, I realized the possible benefits of allowing children with life-threatening illness to tell their own stories.

From there I began research filmmaking as art therapy for ill children and found a major gap in the literature. With that, I knew I had a niche to fill. It was an inspiring experience to feel like I was actually contributing to the field, as opposed to just rewriting what has already been created. I am looking forward to developing this project further and am thankful for my experience in WR 150.

— Lauren Kesler

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## Abstract

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Books (and films) like the teen cancer romance *The Fault in Our Stars* have popularized the “sick-lit” genre in young adult fiction. While the story attempts to depict life with illness, it is, in the end, fiction. Also fictional are the overly tragic PSA’s for research hospitals, where children are often overshadowed by a glamorous celebrity spokesperson. The voice missing in these representations is that of the child. I propose the creation of an autoethnographic film project that will allow seriously ill children to use cameras to express and represent themselves and their illness in the way they see fit. This paper will cover the history and uses of autoethnographic filmmaking, art therapy, and the idea of using filmmaking as a form of art therapy, which is currently missing from most literature on the emerging practice. The opportunity that children will have to film and edit their footage will give them control over their representation, leaving less room for misrepresentation by medical professionals and families, as can often happen when using traditional art mediums. The final films will provide an unfiltered, authentic view of childhood illness for outside viewers while remaining a positive, exciting, and ethical experience for the children involved.

Keywords: pediatric illness, autoethnography, art therapy, self-representation, ethics

LAUREN KESLER

*Prize Essay Winner*

## PAINTING THE REAL PICTURE: THE BENEFITS OF AUTOETHNOGRAPHIC FILMMAKING FOR CHILDREN WITH LIFE-THREATENING ILLNESS

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Nearly every media representation of pediatric life-threatening illness can be categorized in one of two ways. On one side, there is a fictionalized portrayal of life within the walls of a hospital, as seen in books and films like *The Fault in Our Stars*, which suggests that while a life-threatening illness is terrible, it will get you a cute boyfriend, sex, and a trip to Amsterdam. On the other side, there is the overly tragic view of illness: maudlin music, celebrities, bald children, and the concomitant plea for money for research hospitals on televised public service announcements. Both representations work to “oversimplify and misrepresent” disease (Nuñez), inviting the question: What is the experience really like for the young people who live between the walls, wires, and monitors of childhood illness?

Illness thrusts children and families into the foreign environment of a hospital. Here, children are taken from their regular lives and forced into one where pokes, prods, and questions from medical teams take priority over play and activity. Away from the normalcy of daily life, children face new fears about life—and sudden and confusing thoughts of death. A common way to help children cope with the experience is to encourage them to produce art while in the hospital. Tracy Councill, a professor of art therapy at George Washington University, argues that participating in art while ill “can support communication between the patient, family, and medical team and assist families in finding a balance between talking about painful subjects and going on with life” (78). While engaging in art, children are able to express their feelings and concerns in a way that is more comfortable for them than are interviews with therapists and medical professionals. Cathy Malchiodi, an art therapist and clinical counselor,

classifies art therapy as a beneficial communication tool, especially for children too young to fully explain themselves using words (16). While activities like drawing and painting are commonly discussed forms of art therapy, rarely discussed is filmmaking, specifically autoethnographic filmmaking.

Autoethnographic filmmaking offers people an opportunity to creatively engage with their environment, represent themselves as they wish, and produce a tangible product that can be shown to a wider audience. With this in mind, I propose the creation of an autoethnographic film project for children with life-threatening diseases. Putting cameras into the hands of children will give them the ability to ask the questions, represent themselves, and look back at the footage to better understand their new world. The project will enable children to turn the gaze away from themselves and their illness and explore their own curiosities, from interviewing their doctors to filming frightening exam rooms or their fellow patients. Unlike painting or drawing—which, once created, is often examined and interpreted by a therapist, leaving the child out of the process—allowing children to edit their own footage will let them do the interpreting and give them the opportunity to shape their footage in a way that is representative of their experiences.

Malchiodi defines medical art therapy in her book *Medical Art Therapy with Children* as “the use of art expression and imagery with individuals who are physically ill, experiencing trauma to the body, or who are undergoing aggressive medical treatment such as surgery or chemotherapy” (13). This practice originates in the idea that children “use art for self-expression, conflict resolution, and emotional reparation” (16). For children with illness, experiences such as separating from parents, being bed-ridden, and losing weight or hair are all common. Patients dealing with such challenges can feel a sense of a loss of control and helplessness, which art therapy attempts to combat by turning children into “active participant[s] in their health care” (16). Art therapy works not only to distract or entertain children during their illness, but also to help them recognize that they have created something real and “tangible.” For cases of life-threatening illness, this art can become a type of “visual legacy” of their lives and something that children, especially older adolescents, can choose to leave behind for their families as they anticipate their deaths (17).

For children experiencing unfamiliar medical procedures and the sudden discussion of death, art therapy can provide “stability” (Councill 75). For many children suffering from a life-threatening illness, MRI machines and wheelchairs have supplanted playgrounds and sports. Art helps to fill the gap by being an enjoyable and creative activity that does not require much mobility or physical energy. Councill says that art can provide children with the “comfort of touch, the freedom of nonverbal expression, reduction of stress, and the opportunity to exercise a measure of control” (75). For these reasons among others, various art programs are “flourishing in hospitals” and other medical settings in the United States and around the world (“Examples”).

While common art therapy activities include drawing and painting, autoethnographic filmmaking has not yet been seriously considered as an option of therapy in cases of pediatric life-threatening illness. This artistic approach has the same benefits of the traditional mediums, including self-expression, but has an added benefit of allowing the children to gain a sense of self-representation as well. While drawing may enable a child to express herself, a therapist is usually present to analyze the artwork for “what it represents” in the child’s life. For this reason, an outside audience can easily misinterpret the child’s unique vision. However, with autoethnographic filmmaking, the representation remains firmly in the child’s control.

Such filmmaking is not a new concept, and variations of it have existed for many years. In one of the first examples of autoethnographic filmmaking, anthropologists gave 16mm film cameras to members of a Navajo reservation with the hopes of learning about the culture by “put[ting] the camera directly into native hands” (Rangan 147). They originally coined the term *bio-documentary* as a way to describe “a film made by a person to show how he feels about himself and the world” (147). More recently, this idea of using cameras (still photography cameras in this case) to self-document is seen in the 2004 Oscar-winning documentary *Born Into Brothels*, in which photojournalist Zana Briski taught children living in the brothels of Calcutta how to use cameras so that viewers could “see this world through their eyes” (145). The project succeeded in giving the children a chance to represent themselves, as Avijit, one of the children featured, concurs: “It gave me a voice. It gave me a life” (Roston). This pro-

cess has been replicated by projects and organizations including Kids with Cameras (an organization founded by Zana Briski); ZoomUganda, which gave cameras to teenage girls in Uganda to document their lives; and the 2005 documentary *Desire*, which gave film cameras to teenage girls in underprivileged neighborhoods in New Orleans so that they could speak up about teenage pregnancy and other issues of concern (Rangan 151).

The principal assumption informing autoethnographic filmmaking is that people are more open to talking on camera when they retain the power to represent themselves, rather than having a stranger interviewing them. This openness can be seen in the 2014 documentary *Maidentrip*, which was directed by Jillian Schlesinger but was filmed almost entirely by teenager Laura Dekker while on a two-year sailing journey around the world. What is important to note is that Dekker had no interest in having her story recorded and shown to the world, as seen in the film by her annoyance with the media and journalists interrogating her while at port. In fact, she agreed to make *Maidentrip* only after Schlesinger asserted a desire not to “make a film about her, but make one with her” (Kemmerle). By granting Dekker an active role in the production process, Schlesinger gave her a “level of respect” and allowed her to have control over her own representation and the project as a whole (Kemmerle). Schlesinger explains in an interview with Tribeca that the freedom of representation she was given was “very empowering to her” (Kemmerle), and I would argue that it is likely the reason she agreed to make the film.

It is crucial to consider the importance of the camera in projects like *Maidentrip* to better understand why filmmaking would be a beneficial form of art therapy for sick children. There is something about the mere presence of a camera that intrigues people, especially children, and inspires them to start filming. While no single explanation exists, Gerry Bloustien and Sarah Baker have extensively researched the concept as part of their autoethnographic projects with pre-teen and teenage girls, hoping to use the films to better understand the “nature” and “complexity” of growing up (64). Through working with the girls, they began to understand the power that cameras can have in “telling a story of the ‘self’” (69). They explain how, as the camera developed technologically and became more compact and easy to use, allowing people to record with increasing ease, it has become both “voyeuristic” as well as “a means of control” (70). What most

surprised Bloustien and Baker was the allure that the camera possessed for the girls, simply by existing as a source of experimentation. The girls found that being able to represent themselves was exciting and more enjoyable than being filmed and questioned by professionals (71). Bloustien and Baker state that the camera has proven itself to be “a powerful tool for young people in their search and creation of that illusive and ultimately impossible ‘real me’” (76). This search for the “real me” is perhaps simplified by the camera’s unique ability to be turned on the filmmaker, both literally and figuratively, allowing the one filming not only to create compositions, but also to study the visuals and experiences (and themselves) when re-playing the footage.

One of the most relevant pieces of information from Bloustien and Baker’s research that can be transferred to a filmmaking project for children with life-threatening illness is the idea that the girls found filming themselves to be more engaging and less “dull and time-consuming” than when questioned in an interview setting (71). This feeling would certainly resonate with children who spend hours a day being questioned by doctors, nurses, and family. If an external film crew were to enter a hospital in hopes of talking to sick kids, they would likely meet a wall of children unwilling to be poked and prodded by yet another group of strange adults. In contrast, an autoethnographic film project will allow the kids to have “an authoritative voice” (Bloustien and Baker 72) and assume the role of interrogator. The presence of the camera will, in this case, allow the children to do something that drawing and painting cannot do, which is to control the gaze. Whereas traditional art therapy relies on professionals watching the child and interpreting their work, autoethnographic filmmaking will allow the child to watch the professionals and their surroundings from the position of an outsider. In doing so, children will gain the ability to see their world as others do, as the camera works to make, as Susan Sontag would say, “familiar things small, abstract, strange, much farther away” (167). By experiencing this distance, children will gain a new perspective on their illness—and themselves.

If filming themselves will turn the children into outsiders, what will happen when true outsiders are granted access to the children’s world? The idea of having the final films of the children’s shown to a larger audience outside of the hospital does raise some ethical questions. Should people



be given access to children's intimate thoughts and feelings during such a difficult time? As Calvin Pryluck questions in his landmark essay about the ethical questions surrounding documentary film, "What is the boundary between society's right to know and the individual's right to be free of humiliation, shame and indignity?" (24). Audience members watching the children's films may feel uncomfortable, as they are witnessing something that seems far too personal for outsiders to see. As a result, some may argue that films of this nature are unethical and disrespectful to the child and the people in his or her life.

It is true: the ethics of autobiographical documentaries must be treated differently than traditional documentaries. For one, the relationship between the filmmaker and the subject starts with "a level of trust and intimacy never achieved or even strived for in other films" when the film records the personal stories of the filmmaker and his family and friends (Katz and Katz 120). In other words, while film crews usually have to spend months or years building a bond with their subjects, autobiographical film projects give the promise of instant comfort between filmmaker and subject. Watching such a documentary, viewers might question emotional scenes, wondering why the filmmaker chose to film such sensitive material and whether those featured in the film (in our case, friends and family of the ill child) approved of the personal footage being shared. Were the friends and family coerced to participate? Did they agree to be filmed in that compromising position? In the end, determining whether or not a documentary is ethical usually relies on proof of the subject's informed consent to appear in the film, which can get more complicated when the subjects are friends and family of the filmmaker and the scenes are increasingly emotional and intimate (123).

Katz and Katz state that the key question to be asked when dealing with families and friends of the filmmaker is this: "Would the families in autobiographical films have, in similar circumstances, agreed to be filmed by strangers?" (123). They hypothesize that reasons such as "love, guilt, the fear of loss of love" felt toward the filmmaker (in this case, an ill child) may make families and friends agree to appear in a film they would not agree to in other circumstances (124). Katz and Katz believe that "'therapy' does not justify the sort of exposure they [the filmmaker] request or demand of family members" and that many times audiences and critics do not under-

stand “using film as therapy” and will instead view films of this nature as “manipulative” (128). This reaction is likely due to the discomfort audiences feel when viewing something that is so intimate it becomes “too personal,” and thus turns the camera into something “invasive” rather than “an instrument of inquiry” (125). Mark Ledbetter provides insight on the discomfort we feel when we view something we think we should not by noting that since childhood we have been trained “not to look” at painful images (4). This has created a “need to say that we did not see something,” as the word “voyeur” tends to have a bad connotation in our society (4). However, he goes on to argue that “we are voyeurs by nature, and voyeurism is necessary to ethical encounter” (4). In this way, while some viewers of a film about a child with life-threatening illness might say that we “shouldn’t be watching this,” I would argue that it is for this very reason that we should be watching it. Discomfort does not mean unethical, and “not watching” does not equate to “not happening.”

In addition, the consent process of this project—premised on collaboration—is one considered by documentary scholars to be the most ethical option. Pryluck argues that “voluntary informed consent in medical and social research is the protection of the physical and psychic well-being of the subjects,” that “subjects should not be humiliated by the experience,” and should not leave with “lowered self-esteem and social respect” (26). Because in this project the children are the ones doing the filmmaking, there will be no question regarding the well-being of the children participating. No children will be forced into filming, and only those who are interested and properly informed of the project will take part. The key to this project is collaboration between the director facilitating the program and the children and families participating, a collaboration premised on the assumption that “the subjects know more than any outsider can about what is on the screen” (Pryluck 27). In this way, “collaboration fulfills the basic ethical requirement for control of one’s own personality” and we can be assured that nothing will be shown on screen that has not been approved by all of the film participants (28). The goal of this project is to show a personal and authentic representation of pediatric illness. It is a goal that cannot be completed by a fiction writer, marketing team, or film crew. It can only be achieved by granting the children an active and prominent voice in the construction of the film.

Autoethnography is one of the most successful methods to enhance collaboration between children and filmmakers or researchers. This idea is emphasized in a program called Photofriend, which gives cameras to refugee children to tell their stories. The program seeks to gain information about the children for research into refugees but does so in a way that is “unobtrusive, respectful of children’s experiences of adversity, and enjoyable” (Oh 282). The experiences of ill children are clearly different from those of refugee children, but there are parallels to be drawn as we compare two groups of children who find themselves in unfamiliar and frightening places. In regards to Photofriend, there is an approach of “participation and empowerment” for the children being researched and a belief that children should be treated as “social actors rather than victims” (283). In addition, in accordance with the principle of “doing no harm to children,” which includes asking questions that may be painful for the child, Photofriend found that taking pictures eventually resulted in children talking about their painful experiences “without being prompted” (285). In this way, the research process became a safe environment in which the children did not feel pressure to say anything that they did not want to disclose—the kind of environment that my project intends to create.

Doctors, nurses, therapists, and families all want to better understand a child’s experience with illness and need the information to create better treatment plans for future occurrences of the disease. But sometimes the constant interviews and therapy sessions begin to feel too similar to the constant exams and medical procedures. Children are overwhelmed by the attention, inspiring emotional distress. There is a need to study the “victims” of pediatric disease, but there is also a need to remember that these research specimens are people who deserve a chance to share their voice. Giving children cameras to tell their story and express themselves will succeed in being a form of diversion and therapy for a child, while, when viewed by professionals and an outside audience, will also offer a useful insight into childhood illness. It is a mutually beneficial process that allows both sides to gain new and useful information about the world around them. It is art therapy, filmmaking, and research at its best and most ethical.

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LAUREN KESLER is a member of the College of Communication's class of 2016, studying Film and Television. She would like to thank her parents for being a pediatrician and a nurse, so that they could pass on just enough of their passion for sick children to inspire her to develop this project. She would also like to thank Professor Milanese for believing in this paper even when Lauren came to office hours ready to "destroy the entire thing." Lauren would also like to mention that if you happen to be a film producer, she would love to actually make this movie, so please be in touch.