Journal of Medical Humanities, Vol. 27, No. 1, Spring 2006 (© 2006)
DOI: 10.1007/s10912-005-9003-4

Documentary Bioethics: Visual Narratives for Generations X and Y

John C. Stys[1,2]

Published online: 31 March 2006

Narrative bioethics is primarily understood to involve storytelling through the use of literature. This article suggests that other forms of media are necessary to convey stories of an ethical nature to an audience broader than one being trained as medical professionals. "Documentary bioethics" is a manner to present and interpret stories of an ethical nature using forms of popular electronic media in a reality-based documentary style to society at large, specifically Generations X and Y.

KEY WORDS: bioethics; documentary; film; narrative.

In his book,*The Fiction of Bioethics*, Tod Chambers writes: "Ethical analysis ought to concentrate as much on how one sees moral dilemmas as deciding how one should act in response to them."[3] Chambers continues by citing Hauerwas who wrote, "[moral] behavior is an affair not primarily of choice but of vision."[4] It is helpful if this vision is one of the present and not necessarily a vision of the future or the past. I will claim that it is important for a person faced with making a decision about an ethical problem to have the ability to empathize with the subject of the problem. To use a colloquial phrase, one must "put oneself in the other person's shoes." It is this process of shifting one's moral framework from self to other that visually presented images have consistently induced in striking ways.

Some scholars who write about narrative describe literature as the gold standard method for conveying stories. The use of literature is unquestionably effective. This also holds true when discussing narrative ethics or, more specifically,

[1]Loyola University Chicago, Health Care Ethics Program, 6235 N. Kenmore Ave., Chicago, IL, 60660, USA.
[2]Address correspondence to John C. Stys, SJ, RN, MS, MA, Department of Theology, Campion College, 105 Hope Road, Kingston 6, Jamaica, W.I., 876-927-4267; e-mail: stys@jesuits.net.
[3]Chambers, The Fiction of Bioethics, 21.
[4]Ibid.

1041-3545/06/0300-0057/1 © 2006 Springer Science+Business Media, Inc.

narrative bioethics. Even though most narrative ethical material takes the form of literature, I believe (depending on one's target audience) that it can be done even more effectively using a different medium. Ethicists who use a narrative approach should consider using more documentary styled electronic multimedia content as a method of presenting and interpreting the ethical challenges that exist in the U.S. health care system. Specifically, this can be done to assist the current and future generations to confront certain ethical issues. Visually presented narratives can be effectively used in a style that I define as "documentary bioethics," a term which refers to the presentation and interpretation of moral and ethical dilemmas found in the health care setting using a documentary style.

I will examine three questions in this essay. The first is an overview of some of the definitions of narrative in the literature to demonstrate how it is contextualized in the health care setting. The second seeks to expose the limited audience of medical narratives. The third introduces the term "documentary bioethics" and describes its potential applications.

WHAT IS NARRATIVE BIOETHICS AND HOW IS IT USED IN HEALTH CARE?

Within the philosophical and medical literature, three ways of talking about narrative emerge. First, some literature discusses what is simply called, "narrative." Second, there is much medical literature that discusses "narrative medicine." Third, there is a more specialized body of literature that discusses "narrative ethics" or "narrative bioethics."

Narrative can be defined rather simply as a story or the telling of story. Brian Hurwitz describes narrative as "a pattern of events placed in an order of sorts, involving a succession of occurrences or recounted experiences from which a chronological sequence may be inferred."[5] He states that through the use of stories, a person can "enter into other worlds, shift viewpoints, change perspectives, and focus upon the experience of others."[6] Similarly, Rita Charon describes narrative as "the intersubjective domains of human knowledge and activity, that is to say, those aspects of life that are enacted in the relation between 2 persons."[7] Charon cites literary critic R. W. B. Lewis who defined narrative as dealing "with experiences, not with propositions."[8,9] If we desire to "put ourselves in another's shoes," then encountering narratives is one way to do so. The different bodies of literature do not differ significantly on definitions of narrative, but they do differ on the application of narrative to one's field of study.

[5] Hurwitz, "Narrative and the Practice," 2086.
[6] Ibid.
[7] Charon, "Narrative Medicine," 1898.
[8] Ibid.
[9] Lewis, The American Adam, 3.

Championing the integration of literature and medical education, Charon defines narrative medicine rather simply as "medicine practiced with narrative competence."[10,11] To develop this narrative competence, she outlines five goals statements crucial to this integration:

> (1) Literary accounts of illness can teach physicians concrete and powerful lessons about the lives of sick people; (2) great works of fiction about medicine enable physicians to recognize the power and implications of what they do; (3) through the study of narrative, the physician can better understand patients' stories of sickness and his or her own personal stake in medical practice; (4) literary study contributes to physicians' expertise in narrative ethics; and (5) literary theory offers new perspectives on the work and the genres of medicine.

From my perspective, goals number one and three carry the most significance because they help physicians (or physicians-to-be) develop a deeper understanding of the people they serve. Charon describes how narrative competence is constructed through the use of literature including "novels, short stories, poetry, and drama."[12] In contrast to Charon, I suggest that literature is neither the only method for building narrative competence, nor is it necessarily the best depending on one's target audience.

There is other literature that places storytelling in the context of bioethics. This type of narrative application is called "narrative bioethics" or "narrative ethics." Thomas H. Murray delineates four approaches to narrative ethics: "narrative as moral education; narrative as moral methodology; narrative as an appropriate form of moral discourse; and narrative in moral justification."[13] All of these approaches have their place; however, I am primarily interested in developing narrative as moral education and moral discourse. Murray reminds us that children learn primarily through listening to stories.[14] I believe that we never lose our fascination with hearing stories. Most people have had the experience of being in a situation where one loses interest in the subject matter at hand. For example, mind-numbing classroom lectures can sometimes induce sleep (or, at best, daydreaming). However, if the speaker introduces a story into the lecture, one will notice that the audience suddenly begins to listen again. Listening to and integrating the meaning of stories is a natural part of human functioning.

Let us look at the classical example of medical storytelling. The storytellers in this context are medical professionals, most often physicians. The audience is made up of other medical professionals including medical students, residents and nurses. The narrative in this context is the medical case study. The following is an excerpt from a typical medical case study: "M.G. was a sixty-two-year old white female who had undergone a mastectomy for breast cancer. She received

[10] Charon, "Narrative Medicine: A Model," 1897.
[11] Charon, "Narrative Medicine: Form," 83.
[12] Charon, "Literature and Medicine," 599.
[13] Ibid.
[14] Murray, "What Do We Mean," 6.

only three of a proposed six courses of adjuvant chemotherapy because of severe bone marrow suppression. Fourteen months later she was found to have bone and lung metastases."[15] The function of the case study is to convey information from one medical professional to another. For example, the patient is named only through the use of her initials—her identity is hidden from the audience. She is also described according to her disease with medical terminology and in the passive voice, such as having "undergone a mastectomy" and "received chemotherapy." These characteristics do not attempt to illustrate anything beyond the patient's physical situation. The patient is never described as being an active participant in her care. This way of presenting information might be useful to medical professionals speaking to their colleagues, but it does nothing to present the patient's reality beyond her lack of physical health. However, this may be the right type of narrative for this audience.

In comparison, Charon posits that using literature to describe patient experiences does much to increase a medical professional's ability to reflect on topics ranging from end of life issues to women's health and disability.[16] She implies that this is best accomplished through various literary genres, and artists such as Dante, Virgil, Tolstoy, Shakespeare, and Henry James.[17] If using classical literature helps medical students increase their "narrative competence," then it should continue. However, I suggest that this type of narrative does little to present the actual life situations of real people who live in modern times and who are forced to interact with the current health care system. Literature can help a medical professional empathize with the suffering of fictional individuals and, consequently, empathize with their real patients. But using this type of narrative material is inadequate for the moral education that Charon suggests. It does not give the medical professional an understanding of patients' realities.

Before leaving the discussion of narrative, its definitions and current uses, we must place narrative into a philosophical context. John Arras situates the concept of narrative bioethics into three philosophical "formulations"[18] and suggests that the field of bioethics is beginning to embrace a movement that no longer depends only on the "'principlist' paradigm" but rather on narratives that describe the experiences of patients and healthcare professionals.[19] Arras describes three formulations of narrative ethics: "narrative as supplement to an ethic of principles," narrative as "the very ground of all moral justification," and a postmodern approach where the narrator and her story become "substitutes for ethical justification."[20] While the third formulation is controversial and not clearly helpful, the first two positions have distinct pedagogical merit. The first formulation

[15] Ibid.
[16] Crigger, Cases in Bioethics, 38.
[17] Charon, "Literature and Medicine," 600.
[18] Ibid.
[19] Arras, "Nice Story, but So What?," 68.
[20] Ibid., 66.

suggests that principles and theory should not be understood as able to stand alone. Rather, the work of narrative is intimately tied-up in principles and theory in the sense that, "our responses to stories are the ground out of which principles and theories grow."[21] As understood by John Rawls, this back and forth interaction between narrative and principles leads to "reflective equilibrium,"[22] which term describes a continuous interplay between narrative and principles.[23] Followers of this theory believe that principles offer a certain type of guidance, while actual judgments are made at the case level. The judgments made at the case level then help to reformulate the theory and principles that acted as the initial guide.[24]

Of course, without a first narrative or a first principle, nothing else can come about to start the process of reflective equilibrium. Arras' second formulation relies on a view articulated by Alasdair MacIntyre and Stanley Hauerwas that rejects the notion of universal theories and principles. MacIntyre and Hauerwas suggest that theories and principles originate from a master narrative but are always "characteristic of a certain historical tradition."[25] "Universal" theories and principles must, at some point, be founded in certain narrative traditions of human beings. Arras eloquently writes, "the reasoning has to end somewhere, and it ends where it began, with a narrative account of who we are as a people and how we got to be this way."[26]

WHO IS LISTENING? THE QUESTION OF AUDIENCE

The storyteller must know to whom her story is being told. As has been discussed above, the primary audience for literary narratives with health care related content is health care professionals. In other words, only medical professionals, policy makers, philosophers, and few patients are interacting with any type of narrative accounts of health care or bioethics. Some scholars believe that this is adequate and that no further consequences of this limited audience exist. However, there are consequences, especially if one believes in the necessity of educating the current and future generations about the moral and ethical issues in health care that they will undoubtedly face in the future. Society has some responsibility to educate its members about such complex issues, and narrative can be used with other audiences. Thus, as scholars and educators interested in the use of narrative in the health care context, how can we target media to the populations who will benefit from exposure to bioethics? We must first identify those populations and make some initial determination regarding their needs and preferences.

[21] Ibid., 68–69.
[22] Ibid., 69.
[23] Ibid., 70.
[24] Rawls, A Theory of Justice, 48–51.
[25] Arras, 71.
[26] Ibid., 73.

Before we can discuss the preferences of a certain population or generation of people, we must concede that all descriptions are tainted with generalizations. Sherry B. Ortner recognized this when she stated that, "virtually every statement [about Generation X] has been contested at one point or another . . . ."[27] With that said, it is important to look at two generations, which comprise a central core of today's U.S. culture: Generation X and Generation Y.

The literature shows that Generation X includes people born between 1961 and 1981 and makes up about 44 million people in the U.S.[28,29] They have been described as rebellious, anti-establishment, and anxious. Members of Generation X are generally conscious that they have been the first generation unable to achieve a higher standard of living than their parents.[30] They are a generation that, "first and foremost has been about identity through work: jobs, money, and careers."[31]

In comparison, Generation Y includes people born between the late 1970s to mid-1990s and makes up about sixty to seventy million people in the U.S.[32] Also known as the Millennium generation or the Echo Boomer generation, they are the largest population of teenagers in U.S. history.[33] Unlike the general reputation of partying teenagers constantly in motion, Generation Y is a relatively relaxed group. Their favorite activities are described as "listening to music, hanging with friends, going to the movies, dining out, and watching TV."[34] Note that three of the five activities described are media related. However, Generation Y has also been described as being fickle when it comes to media, and research shows that Generation Y responds to media that invokes the emotions, especially humor, and that uses real people in real situations.[35] Research also supports stereotypes suggesting that they enjoy the aggressive style and fast pace of today's media.[36] The influence of the Internet has shaped the belief of Generation Y that the voices of normal people should and can be heard.[37] However, the members of Generation Y do not seem to gather information from the Internet as much as members of Generation X do. In fact, the use of the Internet for information gathering does not rank high when compared to other sources.[38]

In summary, we should be cautious when generalizing the preferences of Generations X and Y although members of these generations clearly depend on music, film, TV, and the Internet more consistently than other groups. With that said, I suggest that if health care professionals and bioethicists wish to engage these

[27] Ibid., 74.
[28] Ortner, "Generation X," 416.
[29] Ibid.
[30] Plotnik, "(Yawn)," 15.
[31] Bernstein and Woodruf, "What Happened to the American Dream?,"80.
[32] Ortner, 421.
[33] Plotnik, 15.
[34] Barrett, "To Reach the Unreachable," 78.
[35] Shepherdson, "New Kids on the Lot," 45.
[36] Morton, "Targeting Generation Y," 47.
[37] Ibid.
[38] Ibid.,48.

populations in a discussion of the ethical dilemmas that they may face in the future, it must be done using an increasing amount of electronic media. In other words, it is important to meet the generations on their terms. Arthur Plotnik understood the importance of audience in general when he suggested that nobody should ignore the preferences of such a massive population of people.[39] We certainly should not overlook these audiences, but, instead, should help to educate and direct them towards having a facility with certain ethical and moral issues that they will face as maturing adults.

DOCUMENTARY BIOETHICS

This brings me to my last question: "How can we better present issues of health care and bioethics to our society?" The use of literature seems to be the most prominent method of narrative to describe and interpret issues of an ethical nature. I suggest an increase in the use of electronic media in a documentary style, which I term, "documentary bioethics." To summarize, it describes the use of film, video, and Internet technologies used to capture and present issues of an ethical nature in the health care setting. As I currently conceive it, documentary bioethics can best be described under three headings: technology, style, and distribution.

First, let us consider technology. Fundamental to my discussion is the use of film or video to convey narrative. With the decreasing costs and increasing quality of digital video, a camera crew can film for lengthy periods of time without drastically consuming their resources. Moreover, a camera crew's ability to be with a subject for long periods of time fosters a trusting relationship to grow between crew and subject, creating an environment which allows the camera to capture intimate and unexpected moments of "reality." An example of this is Richard Kahn's work on the documentary film, *Dreams and Dilemmas: Parents and the Practice of Neonatal Care*.[40] The film is an account of a family's struggle with the decisions surrounding their prematurely born twin boys. The filmmaker was able to build trust with the medical staff and parents by being present with them for long periods of time. In the film, Kahn and his crew are present for very intimate moments that portray the realities of premature birth, neonatal interventions, and ultimately death.

Second, let us consider the style. Documentary is often understood to be synonymous with cinéma vérité, but this is not necessarily the case. Cinéma vérité is a style that stresses an unbiased realism. While striving for realism, a filmmaker would be foolish to believe that this can be done in an unbiased manner. Accomplished documentary filmmaker, Michael Rabiger, defines documentary film as something different:

[39] Ibid., 47.
[40] Plotnik, 16.

> A documentary film can be either a controlled and premeditated essay or something lyrical and impressionistic. It can articulate its meaning primarily through words, images, or human behavior. There seems almost no limits to its possibilities, but at its best, the documentary film reflects a fascination with, and a profound respect for, actuality.[41]

What this "actuality" constitutes is open for debate. Rabiger discreetly reminds his reader that for many large media institutions, the "actuality" of a documentary production is only what can be defended in a court of law.[42] A documentary film should also be able to present reality as it unfolds.[43] Except for documentary films and electronic newsgathering, few other types of media portray events as they occur in real time and rarely do they portray people's unscripted lives. Television, for example, portrays a condensed "reality" through the use of writing and editing techniques. Another feature of the documentary style is that it can educate its viewers without being classically educational. This means that while presenting the reality of a bioethical situation, it can nonetheless attract a broad spectrum of viewers and provoke a reaction from them. The documentary, *Sound and Fury* is an example of such a film.[44] In summary, what we're striving for is the ability to tell "real" stories that involve "real" people in order to help others imagine how they might act in similar ethically challenging situations.

Finally, let us look at distribution. The type of media I am suggesting has the potential to be distributed in many forms, including television, ordinary movie theatres, and the Internet. Public Television has always been a successful outlet for documentary films. Commercial filmmakers such as Ken Burns and Bill Moyers have built their careers on films produced for a broad PBS audience. With increasing bandwidth and advancing compression utilities, we now have the ability to distribute video easily and inexpensively over the Internet.

There are films currently available that illustrate many of the characteristics of the documentary bioethics genre. Independent filmmakers who want special marketing attention for their health care-related films which have turned to companies like Fanlight Productions of Boston, which rents and sells films dealing with disability, nursing, women's health, substance abuse, health policy, death and dying, end of life care, genetics, and mental health.[45] Upon review of the descriptions of the films, many have the characteristics described above, but differ in that the films classify themselves as "educational material." Such a classification carries with it a deadly connotation. Because the films are labeled as educational material, they lose their broader appeal. Let us look briefly at two examples of

[41] Kahn, "Dreams and Dilemmas." - Documentary Film.
[42] Rabiger, Directing the Documentary, 5.
[43] Ibid.
[44] Ibid.
[45] Aronson, Sound and Fury - Documentary Film.

films that can be classified as having the characteristics of documentary bioethics but are not overtly "educational."

An excellent example of a documentary bioethics film is *Sound and Fury*, mentioned above. An Academy Award nominee for best documentary feature in 2001, the film depicts an extended family's struggle to decide whether or not to provide two deaf children with cochlear implants. In the film, the viewer witnesses the love and the anger surrounding their decision-making and demands that the viewer stay with the story to experience fully the hardship and wisdom of that family. A viewer may not only learn something about the ethical implications regarding cochlear implants but may also form an opinion on the issue.

Another film, also mentioned above, is *Dreams and Dilemmas: Parents and the Practice of Neonatal Care*, produced by Richard Kahn, Ronald M. Green, and George A. Little. The producers write that:

> Cinéma vérité films can be exceptional educational material. By reducing the narrator's or the filmmaker's presence, cinéma vérité allows a relatively unhindered view of real practices, issues, human dynamics, and problems. As such, it is a valuable method for advancing understanding and care in difficult and complex areas of healthcare delivery. . . .[46,47]

It is exceptional educational material, indeed, creating a viewing experience in which the viewer feels more like she is in a theatre watching a "normal" film compared to being in a classroom watching an assignment. By the end of the film, it is difficult not to feel part of the story—either identifying with the struggling family, the treatment team, or both.

MORAL ISSUES

When one discusses any use of narrative, it is important to mention some of the inevitable moral issues that arise. First, we must be mindful of who gets to tell these stories. As a society, who do we support in making these films? And how can we determine their different agendas? Would we rather support professional filmmakers (i.e., Hollywood) or independent filmmakers, medical centers, pharmaceutical companies, or patients and their families? Many documentary films are funded by private sources. Obviously, such private sources do not fund projects which do not forward their own mission or values. We must also be mindful of whether or not a society has an obligation to present certain stories over others. For example, are we more or less obligated to present a filmed narrative about a man's struggle with heart disease or a narrative about a child's struggle with AIDS? Third, how do we measure whether or not these stories create change in the viewer? For example, how do we determine the effect of watching *Sound and Fury* compared with the effect of watching *Dreams and Dilemmas?*

[46] Achtenberg, Fanlight Productions Website.
[47] Little, Kahn and Green, "Parental Dreams," 195.

In conclusion, I suggest that in order to engage the current and future generation in a conversation about ethics, it can and should be done using film, video, and Internet produced according to the characteristics of "documentary bioethics." This approach is not without its problems or its potential. However, as medical professionals and those involved in the medical humanities, we must consider our obligation to engage a broader range of people in a conversation about the bioethical issues that they may face in their lives.

REFERENCES

B. Achtenberg, Fanlight Productions Website, http://www.fanlight.com. (accessed 24 September, 2004).
J. Aronson, *Sound and Fury* (USA: Aronson Film Associates, Inc. Public Policy Productions, 2000).
J. D. Arras, Nice Story, but So What? In *Stories and Their Limits: Narrative Approaches to Bioethics*, ed. H. L. Nelson (New York: Routledge, 1997), 65–88.
A. Barrett, To Reach the Unreachable Teen. *Business Week* (September 18, 2000): 78.
A. Bernstein, and D. Woodruf, "What Happened to the American Dream?" *Business Week*, August 19, (1991): 80.
T. Chambers, *The Fiction of Bioethics: Cases as Literary Texts* (New York: Routledge, 1999).
R. Charon, Literature and Medicine: Contributions to Clinical Practice. *Annals of Internal Medicine*, 122 No. 8 (1995): 599–606.
R. Charon, Narrative Medicine: A Model for Empathy, Reflection, Profession, and Trust. *Journal of the American Medical Association*, No. 15 (2001):1897–1902.
R. Charon, Narrative Medicine: Form, Function, and Ethics. *Annals of Internal Medicine*, 134 No. 1 (2001): 83–87.
B. J. Crigger, ed. *Cases in Bioethics: Selections from the Hastings Center Report*, 3rd ed (New York: St. Martin's Press, 1998).
B. Hurwitz, Narrative and the Practice of Medicine. *The Lancet* 356 (2000): 2086–2089.
R. Kahn, Dreams and Dilemmas: Parents and the Practice of Neonatal Care. USA, 1998.
R. W. B. Lewis, *The American Adam: Innocence, Tragedy and Tradition in the Nineteenth Century*. (Chicago: University of Chicago Press, 1955).
G. Little, R. Kahn, and R. M. Green, Parental Dreams, Dilemmas, and Decision-Making in *Cinéma Vérité*. *Journal of Perinatology*, 19, No. 3 (1999): 194–196.
L. P. Morton, Targeting Generation Y. *Public Relations Quarterly*, 47 No. 2 (2002): 46–48.
T. H. Murray, What Do We Mean by 'Narrative Ethics? In *Stories and Their Limits: Narrative Approaches to Bioethics*, edited HL Nelson (New York: Routledge, 1997), 3–17.
S. B. Ortner, Generation X: Anthropology In a Media-Saturated World. *Cultural Anthropology*, 13, No. 3 (1998): 414–440.
A. Plotnik, (Yawn)–That Is So Gen X. *Writer* 115, No. 4 (2002): 15–16.
M. Rabiger, *Directing the Documentary*. 2nd edn. (Boston: Focal Press, 1992).
J. Rawls, *A Theory of Justice*. (Cambridge: Harvard University Press, 1971).
N. Shepherdson, New Kids on the Lot. *American Demographics* 22, No. 1 (2000): 44.