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Beyond the Suffering

—Documenting Human Death and Dying

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Abstract

This paper presents the development of and reactions to a documentary featuring the perceptions that doctors and medical students have about human death and dying. What stands out most overall is the relationship between human death and suffering. The underlying purpose of the documentary is to provide a venue/moment in which to prompt viewers to reflect on human death and dying, and to present a vision of education as a process whereby alterities converge and ideally generate a relationship of enchantment. To accomplish this, the film relied as heavily on iconicity as it did on opportunities to record conversations and face-to-face interactions.

Keywords

Documentary, Death and Dying, Death and Suffering, Art and Representation, Medical Education

1. Introduction

A walk down the corridors of the hospital of a major public university in Rio de Janeiro, Brazil, revealed to us characteristics of academic and medical-care life. The white of the smocks the doctors and nurses wore was a reminder of their commitments to the light of science. Liver-transplant and stem cell-research activities were testament to the advances in medicine under development there. Hopes of preserving and prolonging life through science filled that white space of the university hospital. Notices pinned on bulletin boards announced upcoming conferences, seminars and courses. PhDs and doctors received their training there.

There was one facet of existence that was obscured, however: death. Among the conferences, seminars and courses on that message board, there was not one event addressing the issue of death. The subject was also missing from the curricula of the undergraduate and graduate programs of the medical school there. Should

dealing with the different aspects of end-of-life assistance not be part of the day-to-day concerns faced by medical faculty and their students?

Our review of literature suggested that, in regards to human death and dying, an array of values, ideas and feelings related to fears, interests, anxieties and denials have permeated throughout different groups from various cultures around the Western world.

Ariès (1977) has drawn attention to a historic shift in perception in the modern world whereby death has come to be seen not so much as a natural phenomenon, but as a failure. Death is now hidden. From the philosophical point of view, Morin (1997) has pointed out that, although a natural phenomenon, knowledge of human death is acquired from outside; it is learned. And that would explain the surprise that generally accompanies the news that a life has come to an end. To Elias (2001) the difficulty of dealing with death reflects a stage in our civilization where life expectancies have become longer due to advances in medicine and achievements in the relative pacification in the relationships between individuals and groups, as well as a pronounced individualization in the current standard of living, whereby dealing with different aspects of death and the awareness that one day everybody will die is done in isolation. Gadamer (2006) calls attention to the influences of the scientific proposals of the age of Enlightenment that, upon reaching different segments of the population, were produced "with the aid of the stunning successes of modern natural science and modern means of information as well as the demystification of death as well as the demystification of life". To the sociologist Seale (1998) there are two features to be found in the current ways of dealing with the end of a human life: the influence of modern medicine and the search for meanings for death, which involves emotional components and perceptions on human existence. Kübler-Ross (1996), a doctor who became the foremost authority on the subject of death and dying in the field of medicine, was insistent that comfort assistance is integral for a dying patient's well-being and summed up what changes in attitude she felt were important to make regarding human death and dying: people do not need to suffer on their deathbed alone.

By analyzing these authors, it is not difficult to come to the conclusion that thoughts, feelings and values are associated with the broad and collective ways that different groups perceive the phenomenon of death. The medical-professionals group is just one among so many others that struggle with the issue. If on the one hand, backed by these authors, we can comprehend the fact that death was a subject hardly addressed at all at the hospital mentioned at the opening of this article, on the other it is hard to imagine that the people involved in medical practice and instruction, like the medical faculty and their students, didn't have thoughts or views about a subject so pertinent to them.

Identifying the thoughts regarding death in that university hospital became the aim of a series of studies (Falcão & Bichara, 2009; Freitas, 2005; Almeida & Falcão, 2013). To this end, the researchers based their efforts on the concept of social representation (Moscovici, 2003) and the Collective Subject Discourse CSD (Lefèvre & Lefèvre, 2012) in order to identify and characterize the views of death and dying held by each of the two groups—doctors and students.

The concept of social representation was chosen because the literature review of studies on the topic of death and dying reveals the perception of death to be a social and historical construct. According to Moscovici (2002), when we address, explain or represent a thing or a notion, we do not relate or produce our own ideas or convictions alone, but create and convey a product developed in a number of places progressively, according to an assortment of different rules (p. 63). The subject matter expressed, Moscovici says, refers to the set of concepts, propositions and explanations arising during the course of interpersonal communication characterized by reciprocal influences and implicit negotiations. Thus, through this process, the individuals acquire a common repertory of interpretations and explanations, rules and procedures with close ties to the social and historical contexts that produced them.

The use of the Collective Subject Discourse (CSD) permits a detailed understanding of the views of death held by the groups under study because it is a methodological procedure that identifies patterns of collective discourse without losing the diversity of ideas, images, feelings and values that as a set, through individual utterances, express the social and collective foundations that produced them. This perspective was especially important in the approach to human death and dying, where visual, affective and cognitive perceptions on the topic are historically articulated. One cannot forget that, in the context of medical training and care, the most heavily featured images involve high-tech medical apparatuses. According to the aforementioned authors, such scenes have a major influence on how death and dying is perceived in the modern world. Ideas, values and images would need to be recorded methodologically. A brief explanation of CSD is in order.

The Collective Subject Discourse technique involves the aesthetic principles of iconicity, creativity, and identification insofar as collective thinking is obtained directly from it, as long as the work of the researcher is not interpreted as a schism between the manner of representation and the object represented. The object represented remains personalized, so the individuals will still be able to recognize themselves in the collective testimony. In the experience of our researchers, getting the collective speak for itself, in first person singular, was of the utmost importance. The topic of human death and dying had to be expressed by their own voices; that is, ideally they would be able to recognize themselves in the overall medical community. In other words, in the collective discourse, the diversity, authenticity and involvement of the research subjects would be maintained. It was thus legitimate to use the first person singular in elaborating the discourses of the collective subjects. The result would not only promote reflection on the research topic among researchers, but also among the research subjects.

It is important to emphasize that the key aim of the studies cited here, as previously mentioned, were to give voice to medical doctors and students in regard to how they perceive the deaths they witness on a daily in their professional lives. And our findings showed these voices to be strong; their discourses expressed sensitivity toward human death: they addressed the suffering, the significances of death, and how inadequate their medical training was in preparing them to routinely deal with the end of life. It is clear from their testimony that this causes a great deal of consternation for doctors, students and patients alike. That brought to our attention the perpetuation of shortcomings that one generation of doctors passes on to the next through the medical schooling available to them and showed how important it is to create a forum in which various aspects of patient care and representations of death and dying can be systematically articulated between professional colleagues and students.

In this sense, we understand that the sample groups from the research cited here not only expose the severity of the situation they endured, but show that they are aware that this situation can be avoided: institutional mechanisms and educational processes that involve day-to-day medical and teaching practices can be modified. According to the experts here mentioned, views and attitudes on death are part of broad societal patterns. In pursuing their transformation, both time and educational practices are needed because they stimulate reflection and resignification regarding human death and dying. In short, what needs to be done is to establish a systematic process of reflection on the matter so as to change the conditions dying persons and the professionals treating them endure when receiving and giving care, respectively. Silence is neither the best way to deal with nor the most effective remedy for death-inflicted suffering. Therefore changes should be made to the approach with which medical professionals deal with suffering. And deciding to do so would result in an initiative to increase the dissemination of research findings like those herein reported, and would be a means to intensify interaction between medical doctors and students about the thought-provoking topic of human death and dying.

2. Aim and Justification for Producing a Documentary

Against this backdrop and seeking to create a dynamic and engaging setting that would enable doctors and students to access aspects of the topic of human death and dying beyond what they would find in articles, at conferences or seminars, we produced the documentary that we discuss here. The university where we performed our research does not currently offer any courses on death and dying.

Educating can imply a number of views and practices, as well as ethical stances. One of these views that preserve the ethicality of the process identifies education as a convergence of alterities. In this perspective educating involves a special human relationship where information, knowledge and data can be present, but only in the condition of means and resources for attaining what is most important, the goal: a rigorously respected meeting of interacting individualities aimed at the reciprocal growth of the interlocutors. This convergence should produce a relationship of enchantment among the learners (we are all learners), which relates to the feeling of beauty that emanates from the subject matter exchanged, insofar as said subject matter is firmly anchored in the desire to see the other grow. The educator in this perspective is the anti-narcissist who abdicates from self-enchantment and arousing admiration in the other to concentrate on the text, on the narration aimed at transforming them into potential works of art, for their harmony, grace, charm, and propensity to inspire growth in others. Hence it is clear that there is the possibility of establishing bridges that link education, art and aesthetics. One of these paths has to do with iconicity—and thus an audio-visual medium such as a movie.

Numerous authors, such as Lipovetsky (2007), Debord (2014), Baudrillard (1972) and Bauman (2009), in one

way or another point to iconicity as being a major facet of the contemporary world. In this case iconicity is understood to mean the pursuit and use of technology, resources, processes geared to expressing knowledge, and information through sets of signs of which the act of representing and the object represented are not discontinuous, but analog. Of course, it is possible to use images to lie, seduce, deceive and indoctrinate: much of the mainstream media does this on a daily basis. On the other hand the iconic systems (relying more and more on sophisticated technology) have been facilitating contact that is progressively more direct and closer to reality, thus facilitating the aforementioned feeling of enchantment.

The institution of education, to a large extent, was and still is suffering, burden, pity, backlog; that is, the opposite of aesthetic enchantment, and much of that is due to its almost exclusive use of abstract signs, which through the representer/represented discontinuity that characterizes them, make the act of knowing painful, hard and thankless. Therefore, the creative and ethical use of iconicity can represent a significant advancement in education that strives for learner growth.

The renowned Brazilian documentarian Eduardo Coutinho (2008) highlighted as a relevant feature of the documentary genre of film the possibility of capturing a conversation in the historical context of a face-to-face meeting. In his words, it is the record of the "moment of the encounter" where there would be no desire to judge others or use someone else's words to exemplify the interviewer or documentary-maker's preconceived convictions. Accepting impromptu and friendly relations, where generalizations or rehearsed messages or discourses hardly matter, would be the preconditions for producing a documentary.

If as identified in the aforementioned articles the representations of death in the groups of doctors and students is well delineated by discourses where what stands out is the suffering and recognition that "that's not something you think about", documentaries can offer a venue/moment in which to promote talk and thought about death and dying from the starting point of the personal repertory of the person watching it, the spectator. The documentary allows the spectator to enter into a process of subjective articulation; that is, they themselves construct or reconstruct their own interpretations.

Art of course implies creation, invention and novelty, and as the greater goal of education (as here argued) is to generate enchantment as a means of instilling in learners a desire to grow, the bridges between education and creation through the potentialities of the creative act of generating fascination (with the new, with the challenge) in those involved become apparent. According to Kilpatrick (1978), Dewey defined education as being an equation between interest and effort; in this light, the new, the different (fruit of artistic inventiveness) is, in principle, something that surprises, sparks an interest and an enchantment that, for its part, produces the effort to decipher it and give it meaning. For human beings, to grow, in a negative light, can mean simply to increase in size. But in a positive light, to the growing person, it can mean addition, acquisition, and consequently, novelty, new selves. In this sense, education impregnated by art allows learners to be permanently free to recreate themselves.

The enjoyment of a work of art generates identification (or counter-identification or indifference). To enjoy a work of art is to see oneself in one of Renoir's outdoor scenes, to feel oneself thinking before Rodin's Thinker, to experience old age in a painting by Rembrandt or the melancholy of living in a piece by Debussy. Shifting to the field of education, to enjoy is the pleasure of seeing oneself in the text, to understand a peace of reasoning, to capture a given thread of logic.

In short, it can be said that art infects education (understood to be the meeting of alterities for reciprocal growth) in a positive way when it, through iconicity, is allowed to break down the solution of continuity between representer and represented; when, through creativity, the learner is released to their continued reinvention.

3. The Documentary: Doctors and Patients between Suffering and Death

The decision to produce the documentary (Falcão & Vianna, 2013) was inspired above all by the discourses expressed by the medical-faculty group during the course of the aforementioned research. The following is an excerpt from said discourses:

From the medical-faculty group:

> To deal with human suffering is always distressing, very difficult, very frustrating, very stressful, a very painful experience. It's always very uncomfortable to inform a patient that he has an incurable disease and that he will go on to die. Death is horrible; it would be better if we could just skip that part of medicine. Death tends to bring a heavy emotional load, and doctors, to protect themselves, avoid the dying sick per-

> son. It's hard to maintain the ideal state of balance and make the right decisions. When we graduate, we're awestruck, and when we face the inevitability of our patients dying, we realize we're not really all that powerful after all. And the awe fades. That can really unsettle us. It can be hard to overcome. It can have a major impact on our professional lives. I had a really hard time accepting death and carrying on practicing medicine (apud FALCÃO & BICHARA, 2009: p. 368).

Other research, at the same hospital where the study involving medical faculty was carried out, showed that the students too had issues dealing with the topic of death. The following is a snippet from a discourse from this group:

> It's hard to accompany the process of death. It's a kind of practice that needs to be worked on and perfected with time, through experience in the profession. In theory, through what was discussed in the classroom, maybe I do know how to deal with a terminally ill patient. But I feel patients shouldn't be approached as a whole, but individually. I feel I have to truly practice the profession to really know if I am indeed capable of dealing with them. I don't know, I'll only know for sure when I'm actually faced with the situation. But what I do know is that the little I can do wasn't "learned" at med school (apud FREITAS, 2005: p. 83).

Both discourses corroborate findings from different studies carried out in the field of health, which shows that the local difficulties too are common difficulties in the context of health, more specifically, in the context of medical training and care. In fact, it corroborates what was found in international literature: it is a problem associated with a stage in Western civilization or the characteristics of the modern world so influenced by advances in scientific and medical technology.

It is noteworthy that the documentary was inspired by the discourses of the research subjects but its objective was not to replicate the research findings. The objective was to offer a venue/moment for testimony that promotes reflective spectator involvement. Because it was inspired by research findings, the veracity and legitimacy of the testimony would be in some way implied. Through the said research we know that reflexive and emotional content would be present in the filmed testimony but would not have the connotation of models to be followed nor were they submitted to a performance judgment beforehand.

The documentary features doctors, med students, a nurse and two persons who dealt with doctors in accompanying family members in the process of sickness, death and dying. Doctor and student testimony was included upon their accepting invitations sent out during a determined month and week of the year 2013. We did not concern ourselves with establishing strict participant-selection criteria nor recording a large number of depositions. Given the perspective offered by the review of the literature and the discourses from the aforementioned research, we knew that those who agreed to participate, and were available on the days and hours when we could record, would provide significant material to comprise a panel with the potential to stimulate interaction and engagement on the topic.

Regarding the students, invitations were sent out to around 60 students in a classroom. Seven students participated, while three agreed to have their depositions filmed immediately, which we did, as the film crew was on the scene. We made contact with the medical faculty via email. One of the faculty members was a medical professor who also practiced medicine and is now focused on scientific research in the field of pulmonology; the second, a hematologist and oncologist, had always both taught and practiced medicine; the third was a faculty member specializing in medical psychology and was the coordinator of undergraduate studies the year the documentary was shot. The fourth doctor was included for his experience at public health outposts, though at the time his primary focus was psychoanalysis. We also included one nurse with ICU (intensive care unit) and university-hospital experience. The aim with the latter two participants was to broaden the points of view where the issue of human death and dying is concerned. The aim with this assortment of depositions was to offer possibilities for reflecting on and assigning new meanings to human death and dying. All the depositions were unrehearsed and recorded at one sitting. All they knew was that they were being filmed for a documentary about their experiences dealing with human death and dying.

All the depositions occurred spontaneously: there were almost no interruptions, they were straightforward in their speech and seemed to really be focused on their own experiences. The deposition-opening question was the same for everybody: would you tell us about your experience with death? From that point onward, further questions were posed only in order to further elucidate one statement or observation or another.

The three students gave their testimony simultaneously and spontaneously: having learned they were to be filmed at that moment, they talked among themselves and expressed their thoughts on the matter. They were

thus filmed as a group and interacting in an atmosphere akin to a normal conversation between the three to two young ladies and a young man. As for the medical faculty, a day and time was scheduled on which to meet at their places of work. Each of them spoke for around 50 to 60 minutes, during which time they reflected and shared their emotions on the topic.

The students address their expectations regarding whether they will receive adequate training at school and point out what they foresee as being difficult but necessary challenges: to control their own feelings and manage to establish professional objectivity in their conduct in the midst of human death and dying.

The pulmonologist recounts his initial experiences with human death and dying and underscores suffering as being his principal challenge in the context of patient treatment. The hematologist and oncologist too relates his experiences and emphasizes that the practice of oncology is accompanied by countless situations where he witnesses suffering and death. He asserts that the suffering endured should always be a resource for him to use to help allay the suffering of others, and that everyone should be aware of their role in life: to help others. The third doctor, from the field of medical psychology, speaks not only about the suffering of someone who knows death is near, but about the richness of human character expressed at such moments. He stresses the importance of preparing students for such situations and mentions possible routes for educating them. As for the participation of the two people accompanying their family members, the musician recounts his experience dealing with the prolonged illness and death of his father, whom he says received excellent medical treatment. The other, a retired lady who accompanied her mother throughout what was also a prolonged illness, describes the anguish of being kept away from her dying mother by the doctors treating her on her deathbed. The nurse tells of her time working at an ICU and her first experiences treating dying patients: she was scared and suffered. She also speaks of the pleasure she feels working in such a stressful environment as the ICU and being able to care for patients in critical condition.

We edited the footage to highlight the clarity of the testimony and reorganized the recurring subjects. This was necessary to bring continuity to the film, as well as to maintain the flow that would help keep the viewer's attention. Additional images of the university and university hospital were included for context. The pictures of the hospital building and its corridors as well as the ICU were shot in such a way as to maintain the anonymity of the passersby. The same care was taken when shooting the photos of the classrooms. During the first half of the documentary, when the interviewees make their opening remarks, we opted not to include music, so as not to direct nor smooth over the weight of such context as the voice and its nuances, nor the expressions the interviewees use. After that, halfway through the documentary, music was added to enrich the overall context and make it more dynamic. The music, an original score, is purely instrumental, with classical guitar fingerpicking. It is a small suite in minor key, played with an range of chords. The soundtrack melds with the images and speech without standing out on its own or distracting the viewer. On the contrary, it smoothly helps add intensity to the unfolding testimony.

4. Findings: Knowledge in Action and Educative Intentionality

What we report here is a social representation "put to practice". Using the aforementioned research where we delved into the social representation of death among medical students and practitioners, our findings were resignified by the intersemiotic intervention of the documentary (one language, that of documentary filmmaking, addressing another language, that of science), which is reintroduced for various audiences.

The final version of the documentary, completed in 2013, premiered at Jornada Cientifica, held annually at the public university in the city of Rio de Janeiro, the same location where the documentary was filmed. Jornada Cientifica is an in-house university event that involves the academic community comprised of professors and students. The documentary was screened for an audience responding to an open invitation at the university center for health sciences auditorium. In attendance were three of the documentary participants, who, after the screening, took part in a debate with an outside guest speaker (a sociologist with past experience working with human death and dying). They each gave their impressions about the documentary, after which the debate was open to the public. It is worth noting that all of the participants immediately stated that they were in accord with the result, that they felt their thoughts and points of view had been properly depicted.

The documentary received a warm reception: the debate was intense and characterized both by responses to the documentary and by firsthand accounts of human death and dying from the audience. There were several remarks about statements made by different documentary participants. A process of interaction could be noted

among audience members, whereupon the desire to speak about the topic arose: they voiced their points of view, talked of personal experience, proffered suggestions of websites and books.

The documentary was also shown to audiences of doctors on three separate occasions. All of them were taking postgraduate courses at the university at the time: they came from several different specialties and ranged from 30 to 50 years of age. The different groups reacted in similar ways: A discussion began as soon as the screening was over. Audience members reported their experiences, identified the difficulties and limitations they found in medical training, and touched on other aspects, such as dealing with the families of the patients and with medical technology that often extends the life of a patient unjustifiably. At the end, we posed the following question to each of the three groups: what could we have cut from the film? "Nothing", was the answer in all three cases. Nevertheless, while there was discussion regarding the topic after the screening, there were also some remarks expressing doubt as to whether there was indeed anything the doctors could do given their work conditions. In other words, they focused on the statements from the participants suggesting there was a way through careful attention to soften the plight of dying patients. As for those who took part in the documentary but were unable to attend the opening screening, they were provided a copy of the film to give them a chance to express approval or disapproval as to how they were presented: all of them gave their approval and consented to the documentary being shown.

The documentary was screened in the same manner to different small groups of persons interested in the topic of human death and dying both inside (four five- to nine-participant groups, two of them comprising biology and psychology majors; one of university administrative staff; and one of post-graduate science and health students) and outside the university (three groups of between four and six participants, all of them freelance professionals from a variety of fields). The suggestions of changes to be made to the documentary from persons outside the doctors group were interesting to note. These persons suggested we include statements from a philosopher, the ill or someone suffering from a severe disease, or even that the documentary includes the points of views of other health care professionals. Each screening prompted a process of interaction between the spectators and what they saw onscreen, thence translating into different expressions or remarks: they report their personal experiences and reflections, and suggest things that can be added or improved.

5. Conclusion

This study revealed the potential that the documentary form offers in promoting a shift in the conventional representation of death, which is seen as suffering. The documentary inspired the various groups who saw it to reflect and recount their experiences with the matter. It was never our intention for the documentary to be used as a standard by which to deal with death and dying. Our aim was to stimulate, provoke or promote critical thought on a subject that is also a permanent enigma of the human experience. Our findings suggest that we achieved this aim. Over the years, the different enjoyments give life to a work of art when that work of art, by its own attributes, produces in those enjoying it a feeling that there is something yet to be deciphered: What did Da Vinci mean with Monalisa's smile? Machado de Assis (1838-1908), one of the greatest Brazilian writers of all times, in his book Dom Casmurro, masterfully created the character Capitu, whose enigmatic character to this day urges the question: did she or did she not betray her husband? What could each of us, as citizens of some modern day megalopolis, do differently from the lead character in Falling Down, the 1993 masterpiece by American film director Joel Schumacher. Could the of t-mentioned "Brazilian national character" be the eternal reincarnation of the character Macunaíma, created by Mário de Andrade (1893-1945), one of the Brazilian writers responsible for breathing new life into the Brazilian literary scene starting in the 1920s?

Our enigma here could make way for that which Eco (1965) would call an Open Work but project a direction, an educative intentionality: the transformation of the representation of death with the aim of bringing about its acceptance in our contemporary culture and particularly in the "sanitary" subculture, like "beyond the suffering".

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