

New writings and mediations
in health

From mourning to battle

by Evaldo Mocarzel

The humanism above all

DOI: 10.3395/reciis.v4i2.372en

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Markers

Children and adults with special needs, drama

Sinopsis

The film focuses on deficiencies and potentialities of Down Syndrome, a genetic problem that affects about 8 thousand babies per year in Brazil. The documentary shows the world under the view of a "downian" human being, who has a peculiar and funny, sensorial pleasant point of view, revealing a side on human species that is usually cornered by society in general.

Sinopsis

Original Title: From mourning to battle

Genre: Documentary

Duration: 75 minutes

Year of release: 2005

Studio/Distrib.: Mais Filmes

Directed by: Evaldo Mocarzel

Format: Avi - Size: 996Mb

Theme: Down Syndrome

Cast and Crew

Direction: Evaldo Mocarzel

Screenplay: Evaldo Mocarzel

Production: Leila Bourdoukan

Distribution: Mais Filmes

Photography: Carlos Ebert

The acceptance of individuals having some kind of deficiency by the society is not a normal attitude. Being different always causes surprise. And the more such deficiency is evident, the more difficult is the welcoming look. There is always some astonishment in this almost defensive look. It is, as if, we would tell ourselves: thanks God I am not like this. And when it concerns the parents, maybe disappointment is the first reaction. But soon after this, the same fearful and diffident attitude changes to resignation. Little by little the heart melts down and an interior strength, without a defined origin, takes control of these people. And everything reverts to the individual who demands the highest attention from the parents during the first years of life. They are more fragile and vulnerable to many illnesses.

In the beginning of the movie *Do luto à luta (From mourning to battle)*, the documentarist Evaldo Mocarzel, in a kind of prologue which precedes the credits, shows us a scene of a theater performance at an outdoor theater, where the characters appear wearing masks. This time, however, the meaning is not in the image that the masks are able to produce, but in what they hide. When the actors take them off, we realize that different actors are taking part in the theater performance. All of them have the Down syndrome. The subsequent image is of a nursery where a nurse holds a recently born child and takes him. After this, the parents and a girl with the Down syndrome are in front of the camera. In the passage from one image to the other, the movie director asks the father off the record, calling him by his name, Paulo, how it was for him to receive the news that his daughter had been born with this problem. Immediate reply: *I was punched*. Behind the scene with Paulo speaking, the reflection of an window frame forms the clear image of a cross. Maybe it was a mere coincidence, but, no doubt, the connection between what is being said and what is being seen refers to the popular saying that each of us all carry a cross, that, in this case, it is the daughter with the deficiency. This initial impression is reaffirmed in many statements of parents shown in sequence, and almost always in the presence of the children, who have the typical features of the syndrome. But this impression slowly starts to fade away, and the movie builds up a narrative which undoes the suffering images contained in the first scenes.

A new individual, creative, smart and as normal as any of us appears in the screen. The difference is in his facial traces. They look similar to the Asians. This is the reason for the wrong expression "mongolism" or "mongoloid" for the individuals who present the physical signs of the Down syndrome. But the more touching item in this movie of

Mocarzel is not the possible scientific explanation, but the human feeling it transmits to us. It is something visceral. And we soon understand why, exactly when one of the characters of the movie undertakes the filmmaker role and asks Mocarzel why he is doing a film on this subject. We see the documentarist a little embarrassed and without an objective reply, but with the delicacy of a deep feeling, and the movie is then changed to a scene of a beautiful, nice girl with Down syndrome who is, actually, the filmmaker's daughter. But Mocarzel does not utilize this fact, at any moment, as the main reason for the production of the film. His real purpose is to actually understand and terminate the prejudice which all of us carry in relation to these people with special needs.

The movie has basically three types of image-action. The first set is of the various performances that the characters are able to carry out. From the initial image of the theater, to scenes of dance movements, sports, work, staging and shootings, among many others, what is shown to us is a day-by-day that intends to flow without pedantry or explosive dramatic expressions. There is an essential normality note consistent with the feelings of the movie characters. This central core searches for an intimacy treatment, without invasion. The integrity of the individuals is respected, as well as their freedom of action. Of course some sequences add some spice to the content, not only for the flabbergasting spontaneity of the characters, but also for their ability to perform day-by-day situations. One of the most beautiful scenes of the movie is the morning gathering of a mother and her daughter. An economic cinematographic language is employed, with a rare talent, both of the young girl with Down and the actress playing her mother, and also of the movie director, who was able to extract, from a simple dramaturgy, the lyric content of an intense and transforming relationship.

The second type of image-action presented by the movie consists of interviews, in a chatting tone, which seek to understand what happens when the parents receive the news that their son or daughter was born with the Down syndrome. These moments reveal the intense change which takes place in the life of these people. Some expressions summarize a meaning that touches and awakes the spectators to an active attitude towards life. The initial burden becomes a grace which changes the parents' lives and the family life as a whole. It is as if the outside signs of the faces and bodies were in confrontation with a pure and courageous soul. Facing the pains and the initial mourning on the parents projects a repairing suffering, which, at the same time, brings an almost divine feeling. It is the presence and not the absence which ends up creating a kind of religion in these characters. It is thus

understood the meaning of a doctor's statement who has just given the news to a father and tells him: *congratulations, your daughter has a problem*. It is as if before the birth of the child with the Down syndrome, the meaning of the divine was not present, there not being, therefore, anything to commune with. It is as Giorgio Agamben says: *the sacrifice sanctions in each case, the passage of something from the profane to the holy, from the human sphere to the divine sphere*¹. The Down syndrome must be greeted, in the family, as an asset, a grace. All the conversations with the parents of these people shown in the movie focus the passage they do, from the field of suffer to a complete and generous admission of the good that changed them.

Thus, invariably, during all the narrative, what we see is a kind of justification for something that was "subtracted", in accordance with Agamben concept, i.e., that new being's "normality", which returns as a recomposition or a ritualization of the attitudes. It is interesting to observe how, in the scenes where the children talk and the parents listen, the expectation of the latter is that the former do not say non-senses. A certain relief is noticed when this does not happen. There is a tension in these scenes which disappear with some spontaneous and quick reactions, not thought but lived, from these people which are pure emotion. This way, even understanding and living the problem, the parents, as well as all of us, are unable to perceive the "normality" of the different lives as a counterpoint to ours, very often mediocre and without a path to follow. It is the other side of the coin. The special individuals imply on us a challenging, tense and inquisitive humanity. Under this point of view, they cause us to grow, to improve as human beings: or, as a father that at first did not accept the "gift", declared: as he realized his own reaction, he started to understand his own ego as well. This is it. The syndrome constitutes new individuals. It creates and polishes new sensitivities. It humanizes us. Not only to our neighbors but also to those who are distant, since humanism passes from body to body as in a chain, relationship, networking, or day-to-day experiences.

The third type of image-action of Evaldo Mocarzel's movie is exactly that of the main individuals of the narrative. The main actors of this drama. All of them are lovely. They seem not to have any kind of problem or crisis. We see almost no stubbornness or negative reaction. They are pure and immaculate. Only as an example, we would mention the young couple who preserve their chastity, even sleeping in each other's house, in a relationship that the young people describe as "to stay together" (*). On the other hand, a story is told about a character who lived more than 50 years and

he loved whiskey and women, provided, as far as we can understand, by his bourgeois mother, one of the founders of APAE. This treatment, almost idealized, corresponds to a justified wish, as it is consistent with the dialogues of the parents of the individuals with Down syndrome. For sure, the day-by-day reality of the families is much more thorny and difficult. The nearly playboy type of life of one of the characters, seen in the movie, only in pictures, was only possible due to the rich home where he was born. Therefore, this third narrative part appears to hide the difficulties of the daily struggle with the individuals that have the Down syndrome. Of course that indirectly these difficulties become explicit in some parents testimonies, such as for example, the ones who report a serious illness diagnosis, which very soon afterwards was not confirmed, and how the news were received in two phases: in the first with great fear of a possible loss and, in the next, as the most extraordinary news ever received by them. At the minimum, frights are lived day-by-day. A simple flu may become a serious illness for an individual suffering from this deficiency. Anyway, although the movie does not make these problems very explicit, this does not seem to be a problem, since its purpose is not to report a situation, but to awake a supportive feeling, the understanding and the action in favor of the individuals suffering from the Down syndrome.

In addition to the social prejudice, the special individuals are also a target to a science still without safe answers. The origin or the reason of its manifestation in a person is unknown. It is only known that, biologically, this situation may occur under certain circumstances, but its manifestation is not predictable.

These two ways of characterizing the problem – the prejudice and the science – are the background of Evaldo Mocarzel's movie. Its narrative intends to give voice to the different actors involved in the problem: parents, doctors and the special individuals. These voices constitute a unique and well intended speech about the symbolic representations of a beneficial illness, as it brings the good. The deficiency, as such, is a mere accident. The person is constituted and lives, in the majority of the cases, an existence of happy innocence, which is almost never given to the so-called "normal individuals".

Mocarzel, through his movie, makes the restitution of a human condition inherent to these special individuals, in what they have of more essential and dignified, and to all of us, the understanding of how far we are from the human more than human. The etymologic meaning of the word sick (in Portuguese, *doente*) is exactly belonging to the individual (in Portuguese, *do ente*), i.e. belonging to the living being. The illness is, in any degree it is manifested, of the nature of the living being. *From mourning to battle* reports experiences

which touch and build up an acceptance way of looking at the special individuals who help us to understand ourselves a little better, as part of the humankind which is inherent to us.

(*) Translator's note: "To stay together" is a colloquial expression in Portuguese used by the young generation, to describe a relationship between a couple which does not imply, at least in the early stages, in full commitment and may be merely a provisional and temporary relationship.

Notes

1. AGAMBEN, Giorgio. *O que é o contemporâneo? e outros ensaios*. Chapecó: Argos, 2009

Bibliographic references

AGAMBEN, Giorgio. **O que é o contemporâneo?** e outros ensaios. Chapecó: Argos, 2009.