Impacts of a documentary on the daily lives of mothers and children with disabilities: an analysis of cine debates

Abstract  The article analyzes the impact of a documentary on the daily lives of mothers and children with disabilities, exhibited at conferences, festivals, universities and schools in Brazil, Colombia and Japan. Produced by film and health professionals, social scientists and a women's network, the feature film “A special day” was awarded at Assim Vivemos VI International Disability Film Festival (2013-2014). The objective is to analyze the impact of the film and its diffusion among professionals and students from health and education areas. We adopted a methodology of cine debates that were recorded, transcribed and coded. The circuit toured 22 locations with one or more exhibitions for 3.370 people, of which nine presentations were analyzed. Our interpretations were guided by the notions as life account, biographical pact, imaginary and social representation. We analyzed gender issues, family and maternal care; reactions, adaptations and life after the diagnosis of disabilities; discrimination and prejudice; school and inclusion. The study showed that the communicative and expressive power of film becomes a powerful social technology to address gender, maternity and disability as an important and strategic issue for public health in the country.

Key words  Documentary, Disability, Gender, Motherhood, Social technology


Introduction

This article aims to analyze the impact of a documentary showing the daily routine of ten mothers in caring for their children with disabilities, exhibited in cine debates over two years in Brazil, Colombia and Japan to audiences of health and education professionals and students. The development and production of this film were based on two national and international research projects, involving science and cinema professionals, family members and the professional staff of institutions in the health and disability area, with the support of the Japan International Cooperation Agency - JICA and the Research Support Foundation of Rio de Janeiro (Fundação de Amparo à Pesquisa do Estado do Rio de Janeiro - Faperj). The film takes a new look at aspects of the mothers’ lives and how they face up to the challenges posed by the disabilities. As a contemporary documentary, through various daily routines and thematic blocks, it joins narratives, reflections, photos and scenes, past and present, forming a lively and dynamic mosaic that encourages new outlooks. In this analysis, we will show how the communicative and expressive force of audiovisual language becomes a powerful social technology for developing a relevant and strategic theme for public health in Brazil.

According to Nóvoa et al., there is a close link between cinema and history, animated image and reality. One can sense the weight of the past and be attracted by the novelty the story evokes. Pires and Silva speak of cinema as a cultural artifact that projects itself as a kind of discourse and contributes to the construction of social meanings, helping to disseminate new and inter-subjective knowledge. Cinema as art is capable of shaping opinions, eliciting reflection, and can be used as a strategy for demystifying prejudice and taboos. Codato considers that the main purpose of image in the cinema is to seduce the eye and seek the interpretation, the sense and the meaning in the spectator.

Here, cinema is treated simultaneously as an object and instrument of research. As a produced object, it provides an approximation to the real world, to the concerns and stories of anonymous lives, helping to depict the daily routine and life in societies. As an instrument, it becomes a method, a way of perceiving and understanding the world, dealing with reality, revealing a society’s way of thinking and its representations. Observed and analyzed, it evokes ways of understanding, communicating and being in touch with oneself and others. Thus the use of cine debates constitutes a creative methodology for applied research in social and human sciences.

According to Fróis, in a documentary film, the filmmaker winds up by recreating or reinterpreting the reality he portrays, because the genre allows him to act like a creative artist. Farina maintains that a documentary should be understood as an original production, with conceptual choices, theoretical and technical, of framework, characters and organization of the final production. The author and director play an important role in the way in which the facts are portrayed, hovering on the thin line between fiction and reality. As Mascarello sees it, if, on the one side, the contemporary documentary “constructs a flight line from the surfeit of reality that overwhelms us, on the other, it turns towards a ‘reality’ that escapes us and challenges us in its inextricable exteriority”. In this respect, Farina concluded, a documentary production is not a “reflection of the actual”, but a collection of material that stimulates social debates based on a slice of reality.

This film, produced and handled as a social technology strategy, aims to challenge stereotyped and reified views of the families, the mothers and the disabilities, focusing on the differences of gender and the role the woman plays in this life path full of stumbling blocks and challenges. We start from the assumption that cinema as art, in particular the film in question, affects the social imaginary, informs about the daily lives of the mothers and children, and is also a powerful tool for tackling prejudice and discrimination. According to Pires and Silva, and based on Walter Benjamin, imagistically, film facilitates work on processes of sociocultural alienation and enables the building of new knowledge, initiation of new discourse and, through dialog, reaches subjects and promotes intersubjective processes.

From recollections of the pregnancy, the initial and later difficulties of the child and communication of the diagnosis to the challenges of infanto-juvenile development, the families come up against uncertainties, the couple faces emotional difficulties in assimilating the news that initiates a difference, the mother tends to assume the daily tasks of intensive care, and the professionals have difficulty in giving the diagnosis, guiding and providing support in the most difficult stages of the life. The coldness and silence, the impersonal and distant contact, the omission of information reveal in the expressions of the health or education professionals that the problem is worrying and serious, the child is not go-
ing to develop “as expected” and that the school will have difficulties in receiving it11,12.

On account of the disability, expectations concerning the child’s future start to unravel and a fatalistic and prejudiced tendency to appear on the part of professions in the face of the parents’ difficulties11, shot through with feelings of anguish, despair, fear, sadness and shame, particularly affecting the mothers, not always free to cry and whose pain is barely understood, with many seeing family members and close friends drift away13. In Western and Eastern societies, domestic tasks and child care are women’s responsibility. Thus, as the main carers, mothers are at risk of stress on account of the demanding daily routine in which they sacrifice their love life, social and professional lives, as a woman and wife14. Motherhood of a child with a disability is unique, imposes complex and challenging experiences, involves uncertainty about the future, unknown and unpredictable, requires specialized help, a support network and social support15–17. There is much we need to understand in our civilization about the necessity for family, technical, social and religious support when a child’s limitations are substantial.

Based on the idea that society in general is unaware of the challenges and barriers faced by families and children with disabilities in the course of their development and social inclusion, the feature-length film “A special day” emphases the mothers’ experience of caring and their relationship with their special needs children, the family, school and society. The documentary gives an account of children, young people and adults with various types of disability, neurological syndromes and autism, to a severe, moderate or slight degree. The circuit of cine debates, with a view to raising awareness among health and education professionals and the public, was raised for post-production of the film A special day, distribution and organization of up to ten cine debates in schools, universities and congresses, with a view to raising awareness among health and education professionals and the public in general.

Methodology

First phase, with financing by JICA (2006-2008) – Amorim et al.16 participated in the “Multi Site Study on Depression of Mothers of the Children with Intellectual Disabilities and/or Autism”, backed by the Japan International Cooperation Agency (JICA), Japan League on Developmental Disabilities, with scholars from four countries. With JICA’s support, Amorim et al.16 produced a first documentary, “Above the Waves” (28 minutes), based on interviews with mothers and children with intellectual disability and autism in Brazil, Colombia, Malaysia and Thailand. In the video, they draw attention to the similarity of the women’s experience, despite cultural differences. On showing the video to mothers of “special” children in Brazil, we were surprised by how they felt free to speak, exchange, share and recall their experiences.

Second phase with JICA financing (2011-2013) – This result lead us to invest in a second Brazilian documentary for use as a social technology tool for tackling disability in collective health. Through the “Very Special Women Network” project, sponsored by JICA, the filmmaker Yuri Amorim, assisted by Annibal Amorim17, produced the documentary A Special Day (80 minutes), in partnership with the Instituto Educateur, Kinera Produções, the Centro de estimulação e psicopedagogia Criart and their families. The interviews and the daily routines were filmed after definition of the guidelines for the script in six meetings between the network of women, the professionals and the filmmaker.

Third phase with Faperj financing (2013-2016) – Cavalcante18 set up the project Gênero e Deficiência retratados no cinema: biografias em debate (“Gender and Disability portrayed in the cinema: biographies under debate”), sent to the Office of the Vice-President for Environment, Attention to and Promotion of Health/Oswaldo Cruz Foundation, supported by the Instituto Educateur, Kinera Produções and Criart, as well as the Veiga Almeida University/Integrated Social Practices Laboratory, of the Federal University of Rio de Janeiro/National Museum. Thus funds were raised for post-production of the film A special day, distribution and organization of up to ten cine debates in schools, universities and congresses, with a view to raising awareness among health and education professionals and the public in general.

Content of the film A special day – The feature-length film introduces different ways of looking at gender and disability. It accords visibility to the plurality of experiences that accompany the arrival of a child with a disability, communication of the diagnosis, the impact of the
news on the family and the disability in the lives of the women, mothers, wives and professionals, the adjustments they go through, their pain and achievements, what they learn, what the children with disabilities teach them and what they have to say to the world about their experience. It starts with the question: “If your life was a film, what could not be left out?”; and ends with the thought: “What would be a special day for you?”, when the notion “special” used by the mothers, on referring to their children, acquires singular meanings and concepts in plays on words.

Organization and systematization of cine debates – Exchanges were organized with events that permitted exhibition of the film in eight Brazilian towns and in Bogota/Colombia and Tokyo/Japan. A total of 22 cine debates were held, and nine meetings with health and education professionals and students from primary to post-graduate level were recorded in full. Debates were held after each showing, with the participation of the mothers who took part in the film, the filmmaker, social scientists or professionals and educators, who enlivened the exchange with the audience. The public’s reactions were documented in films and audio recordings, transcribed and organized in an analytical table showing the subjects, what was said and the relevance attributed to the film.

Analysis of the data – The transcriptions were grouped by events and exhibitions linked to health and education and the material was organized in narrative units, by subject and associated ideas. A cross reading enabled an analysis of relevant categories, taking into account the audiences and their particularities. Field impressions, theoretical reflections on documentary cinema, disability and family, gender and motherhood, as well as concepts that guided the interpretation of narrative and social contexts: Daniel Bertaux’s9 idea of a “life story”, Philippe Lejeune’s20 “biographical pact”, the “social imaginary”, approximating cinema and history, according to Nóvoa et al.1, and the notion of “social representation” for Codato4.

We started with Daniel Bertaux’s9 notion of “life story”, which considers the story of a life as told by the person who lived it. What appears to be the basis is merely one facet of the person. As the documentary combined a number of “life stories”, with different profiles, the resulting diversity was such that the contrast between the reports brought about a saturation point that renders the selection representative. Even faced with a “biographical pact” or an “authenticity pact”, as Philippe Lejeune20 points out, we will be heedful of the relativity of the events and the adventure of the art of speaking about oneself. As Nóvoa et al.1 puts it, in the close relationship between cinema and history we perceive the “social imaginary”, confirming the socio-histories as representations and their anchoring in a sociocultural context. In Codato’s4 view, film enters into a dialog with the “social representations” in their historic, social and aesthetic bias, in the power of the cinematographic image, revealing mechanisms that lie behind the impression of reality. The representations stimulate reflections based on the images and the relationships that one human being establishes with another.

The limitations of the study lie in what it was possible to record and compile of a wide universe, in the analysis of words taken out of their conversational environments and in the risk of reducing plural and polysemic interpretations attributed by social players. Taking these points into account, the advantages of the analysis reside in the opportunity to compile and analyze content evoked by exhibition of the film and the debate, differentiating by target audience and the most expressive themes and emphasis, and as far as possible understanding the differences of discursive contexts and the atmosphere noted.

Results and Discussions

From the initial aim of distributing the film A special day and holding eight to ten cine debates, noting the film’s impact on health and education professionals and students, it’s fair to say that we have progressed further than expected, in that the film seems to have “grown its own legs” and is blazing the trail. One showing aroused interest in further showings, and the congresses and events provided opportunities for the protagonist mothers, production team and researchers to participate. Schools and universities, professionals and students became interested in seeing the documentary and helping to organize the debates. The work involved with the film exceeded expectations and it was therefore necessary to establish a profile for the events that would be closely monitored, filmed, transcribed and analyzed.

We will first present the circuit of cine debates in Rio de Janeiro, in Brazilian states and in two countries that have partnered us in various stages of previous projects, Japan and Colombia. We analyzed cine debates held at two scientific
events, two health education graduation and post-graduation events, two primary school and two high school meetings and one focusing on public policies. We will now present reflections on the impact of the cine debates by group analyzed. (1) Health professionals at scientific events; (2) Health professionals and graduate and post-graduate students; (3) Primary education teachers and students; (4) High school teachers and students.

Between August 2013 and March 2016, as shown in Table 1, the A special day film circuit included one or more showings in eight Brazilian towns (Teresina, João Pessoa, Manaos, Belo Horizonte, Rio de Janeiro, São Paulo, Brasilia, Santa Catarina), in Tokyo, Japan and Bogota, Colombia. Specifically in Rio de Janeiro, where we were able to monitor it more closely, it was shown in 13 different venues. The film was discussed in seven congresses, seminars and forums, two international, three national and two regional, an estimated audience of 790 people. The major events that exhibited it considered the theme of attention to health, mental health, disability, autism, occupational therapy and humanization, with the emphasis on human rights, citizenship and diversity. Included in the 2nd ABRASME Film Festival Vida em Foco (Life in Focus), the documentary A special day followed an itinerant exhibition circuit through the Amazonian riverside communities in 2014, at the end of the 4th Brazilian Mental Health Congress, giving visibility to the various productions there.

The film’s initial landmark was its first showing, at the 1st International Healthcare Congress, in Teresina (PI), when it still had a running time of 90 minutes. In response to audience feedback, the filmmaker and director fine-tuned and cut it to achieve a final running time of 80 minutes, and this version competed and was selected in its first festival. In the Assim Vivemos (How we Live) 6th Disability Film Festival, held at the Banco do Brasil Cultural Center between 2013 and 2014, A special day was exhibited six times in Rio de Janeiro, three in São Paulo and three in Brasilia, with a debate in each city. The documentary was considered one of the five best of 26 films from 17 countries (Australia, the United Kingdom, Canada, Israel, Russia, Brazil, Holland, France, Norway, Spain, Scotland, Iran, Belarus, Bulgaria, Poland, Germany and the United States), awarded the prize Mulheres Guerreiras (“Warrior Women”) by the jury, and “best film” by public vote at the end of the circuit. As shown in Table 1, the film was exhibited at eight festivals and events, in institutions and companies (OAB, SESC, SESI, Petrobras) and film festivals (Psicodália Festival), to an estimated audience of 1,110 people.

Finally, the film was shown in cine debates in universities and public and private schools in Rio, to an audience of 1,470 people. In all, between congresses, seminars, festivals, events, universities and schools, the majority in Rio, the film was exhibited to some 3,370 people – health and rehabilitation professionals, family members, people with disabilities, graduate and post-graduate students and professors, primary and high school teachers and students. The following analysis includes reflections on the film in Brazil and Colombia. We draw attention to the interest of a professor from the Social Service department of Japan Women’s University, who included the film in her classroom methodology.

Cine debates between health and education professionals

(1) Health professionals at scientific events: For public health professionals, the film produced an overall view of those who look from the outside, a new way of seeing after an empathetic approach and a change of view concerning the professional way of acting. It presents an overall and plural view of what it means “to be the mother of a child with a disability”; casts a sensitive eye on the mothers and carers, gives a voice to those who undergo the experience. The film gives depth, by reproducing words taken from daily lives. There were mothers in the audience during the debate, who gave their views: “It was extraordinary, the film portrayed what we experience, it showed our expectations and sorrows”; and siblings: “My mother had to learn to be a nurse, a teacher, and to fulfill various social roles to help my disabled brother”. It emphatically brought some people closer to the reality of these mothers of “special” children, in comparison with other mothers, generated a recognition of the investment in the child and their resilient attitudes. One aspect of the film that caught a social scientist’s attention was “the role of affection”, something that requires a major psychic effort in extreme situations. He therefore concluded that these families are “special” in that they sustain affection that is demanding on a daily basis and is often given without support, without other structures, with no chance to catch a breath and recover vitality.

It was striking that over half of the stories analyzed stressed that the film caused a change of view in relation to professional practice, making
Table 1. Cine debate venues in Brazil and abroad (2013 to 2016).

<table>
<thead>
<tr>
<th>Location and Forums</th>
<th>Exhibition of cine debates</th>
<th>Target public</th>
<th>Total</th>
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<tr>
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<tr>
<td>Japan / Tokyo (2013)</td>
<td>1 ASSIDD Asia-Pacific 3rd Regional Congress</td>
<td>Rehabilitation professionals</td>
<td>50</td>
</tr>
<tr>
<td>BR/PI-Teresina (2013)</td>
<td>1st International Healthcare Congress Evidence in primary care and healthcare networks - Conference: Rights of People with Disabilities</td>
<td>Health professionals and family members</td>
<td>250</td>
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<tr>
<td>BR/AM-Manaus (2014)</td>
<td>4th Brazilian Mental Health Congress - ABRASME 2nd Life in Focus Film Festival Human Rights and Mental Health (circuit in Amazonian riverside communities)</td>
<td>Health professionals and family members, communities</td>
<td>120</td>
</tr>
<tr>
<td>BR/MG-BH (2014)</td>
<td>6th Seminar on Autism - Minas Gerais</td>
<td>Health professionals and family members</td>
<td>100</td>
</tr>
<tr>
<td>BR/RJ-Rio (2015)</td>
<td>14th Brazilian Occupational Therapy Congress - Citizenship and Human Rights From financing to practice</td>
<td>Health professionals and families</td>
<td>110</td>
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<tr>
<td>BR/RJ-Rio (2015)</td>
<td>1st HUPE Humanization Forum Pedro Ernesto University Hospital</td>
<td>Health professionals</td>
<td>50</td>
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<td><strong>Festivals and Events</strong></td>
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<tr>
<td>BR/RJ-Rio (2013)</td>
<td>Assim Vivemos (How we Live”) 4th International Disability Film Festival</td>
<td>Open to the public</td>
<td>800</td>
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<tr>
<td>BR/SP-SP (2013)</td>
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<tr>
<td>BR/BsB-DF (2014)</td>
<td>Banco de Brasil Cultural Center/Culture Ministry Psicodália Film Festival</td>
<td>Festival audience</td>
<td>100</td>
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<tr>
<td>BR/RJ-Rio (2014)</td>
<td>Brazilian Bar Association, Rio de Janeiro Branch (Ordem dos Advogados do Brasil OAB-RJ)</td>
<td>Open to the public</td>
<td>50</td>
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<tr>
<td>BR/RJ-Rio (2014)</td>
<td>Social Services provided by Commerce, Rio de Janeiro Branch (SESC-RJ)</td>
<td>Open to the public</td>
<td>80</td>
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<tr>
<td>BR/RJ-Rio (2016)</td>
<td>Social Services provided by Industry, Rio de Janeiro Branch (SESI-RJ)</td>
<td>Open to the public</td>
<td>40</td>
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<tr>
<td>BR/RJ-Rio (2016)</td>
<td>Petrobrás Distribuidora SA PAE Program - Special Care</td>
<td>PAE family members</td>
<td>40</td>
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<td><strong>Subtotal 790</strong></td>
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<td><strong>Universities and Schools</strong></td>
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<tr>
<td>BR/RJ-Rio (2013)</td>
<td>Veiga de Almeida University, 5th LAPSI Meeting Masters and Doctorate in Psychoanalysis, Health and Society</td>
<td>Students and professors</td>
<td>310</td>
</tr>
<tr>
<td>BR/RJ-Rio (2013)</td>
<td>Celso Lisboa University Center, Psychology Week</td>
<td>Psychology students</td>
<td>80</td>
</tr>
<tr>
<td>Colombia-Bogota (2014)</td>
<td>University of the Andes Masters in Public Health and Social Development</td>
<td>Students and professors</td>
<td>30</td>
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<td>BR/RJ-Rio (2014)</td>
<td>Federal University of Rio de Janeiro Casa da Ciência (House of Science) photographic exhibition: Além do Olhar (Beyond the Eye)</td>
<td>Open to the public</td>
<td>120</td>
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<tr>
<td>BR/RJ-Rio (2014)</td>
<td>Governor Roberto Silveira Educational Institute, Raul Cortez Theatre High school pupils, teachers and family members</td>
<td></td>
<td>800</td>
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<tr>
<td>BR/RJ-Rio (2014)</td>
<td>Barro Branco Municipal School, Duque de Caxias Primary school pupils, teachers and family members</td>
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<td>80</td>
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<td><strong>Total abroad 2 venues</strong></td>
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<td>1,470</td>
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<td><strong>Total in Brazil 20 venues</strong></td>
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<td>3,370</td>
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professionals rethink their way of seeing, hearing, perceiving, feeling and acting: “Professional people need to know how to share and hear, and to shed the fear of being creative”. They acknowledged the importance of the exchange of views between mothers and professionals, the need to act in a more integrated way with the subject and their family, the importance of a support network for mothers and carers: “As a nurse, I feel guilty, because I never saw this side of things, I shall provide more help and see how the mother feels”. This proves that, as stated by Naujorks et al., cinema is a powerful pedagogical tool: “The actual representations of people with disabilities can be redefined, repeated, or brought up for discussion, expanding the possibilities of the individual and collective imaginary of people with and without disabilities in relation to those with disabilities”.

(2) Health professionals and graduate and post-graduate students: The importance of listening to families building strategies that meet their needs, the importance of a “breathing space” to enable a mother to be a woman, as well as the mother of a disabled child: “The film showed us a carer’s strength and energy. Their sense of life has changed, but they have to find strength to cope with the fate the world has reserved for them in order to live”. The importance of empowering mothers was emphasized: “We have to strengthen the women, because an empowered woman cares for the family, will track down resources, talk to the husband and mobilize the community, so we will be reinforcing the network”. The specific function of gender is considered, the woman’s role in the family as the one who provides daily help for the more vulnerable members and has a strategic caring role: “The idea is not to cut out the father, the siblings or even the grandfather, but to understand that the mother has a specific role because she’s a woman, in most cases, the one who will provide care or abandon. So, to prepare for this situation, who should we strengthen? The woman?” A woman who manages to find a space to care for herself, as well as caring for others, will be contributing towards fulfilling her social role well and fighting a source of chronic stress. In the words of Neves and Cabral: “Once empowered, a woman can demand her rights, fully exercise her citizenship, ensure quality care for the child, share decision-making with the professional who attend her sons and daughters and be effectively included in the caring process”.

The film presents situations in Brazil similar to those observed by professionals in Colombia - the similar incidence of abandonment by the fathers, the fear of dying and the worry about who will care for the child, the need to find strength to promote inclusion. For these reasons, the film was considered a model and an example of a way of acting with people with disabilities. As the film “Above the waves” shows, thematic similarities of the challenges for mothers and families are to be found in different cultures and societies.

The advantage of film as art and social technology is to retrieve the subjects’ experiences, the interaction between mothers and children, the carer’s suffering, and to give visibility to the matter. “The documentary is beautiful, it shows the family life that we don’t see”, said one professional. The film shows one thing over and above the daily events of professional practice and research: “It’s one thing for you, a researcher, to transcribe the mother’s voice, and then interpreting it, but however much you effect the phenomenological epoché and reinterpret the words, it’s you speaking, it’s not her”. The conclusion is therefore that: “when we stop to hear what she has to say, we realize how much we have to learn from these families, we’re not the only experts, but we also have to learn and they need to act more as partners, we have to spend more time with them”.

On this point, the film gave rise to a very important consideration, a change of view and an understanding of the need to recognize the richness of the strategies these mothers and families create for facing up to the disability, the way in which they produce everyday knowledge that needs to be seen and better understood: “There are many more tools that are developed and that the health or rehabilitation professionals don’t see because they only recognize their own tools, not those built by the families”. This discovery of families as builders of a stock of knowledge, alongside the traditional scientific knowledge, could result in advances: “We need to open up a field of investigation to find out more about the tools built by these families; and how they can suggest tools, think of tools, in other words, involve them in this construction of knowledge and the state of knowing”.

In the book Pessoas Muito Especiais (Very Special People), Cavalcante reveals a wide variety of experiences, strategies, practices, tools and knowledge developed by these families. However, the documentary is a quicker way of evoking new viewpoints, confirming the art’s importance for the production of knowledge: “The film makes us reflect (...) invites us to assume this social responsibility as health professionals, as public health
workers”. The cinema, as an art that gives wings to the social imaginary and stimulates transformation in social representations is highlighted by Silva, Nascimento and Silva: “we understand cinema as an art that expresses a certain view of the world, with philosophical, aesthetic, ethical and educative content, that enables and favors different apprehensions of this reality situated in a historic-social context”.

(3) Primary education teachers and students: A school that stands out for its social and political participation and engagement, in both regular teaching and scholastic inclusion, was chosen to participate in this debate. There were two meetings, which also included some parents and guardians, held in a festive atmosphere. Among the relevant themes highlighted were differences of gender and motherhood, questions of school and professional practice, discrimination and prejudice and public policies. Attention focused on the impact on the life of the couples, the separations, the absent fathers, the mothers left alone and accompanied. The film shows the viewpoint of the mother, the woman, in interaction with the family; and learning about this feminine experience helps us to understand them. The mothers’ lack of time for themselves was noted - how much they need the time to be a woman, how greatly they feel they are losing various rights of life and coexistence, of going to the doctor, sleeping, enjoying themselves and even the “right to die”. As Falkenbach et al. put it, “talking about and studying the matter of the disabilities can provide useful information, however it is living and coexistence with these people that can promote in-depth learning and new views”.

A number of educators who spoke recognized the importance of the school’s and the families’ participation in the children’s development and inclusive education. On the other hand, the school’s commitment to socialization, to fighting prejudice and respecting differences was also discussed. “The film gives us a jolt. The school starts to think of itself as a challenge, that of not only receiving the child (with a disability), but of feeling itself called upon to go a step further - what strategies for developing this individual can the school propose to the family?”. The film also lead educators to think about a change of attitude, seeking to find ways of giving the mothers more support: “I used to think that it was good to listen, but it’s not enough, we need to develop strategies”. There was also a change of outlook and posture, a search for another way of listening, more attention and care in building relationships, better sharing of the responsibilities, working together, teaching appreciation of life, expanding the debate in schools: “What does it mean to be in a relationship? What is the school’s responsibility? What is the family’s responsibility? (...) when we offer special needs teaching, we have to encourage full development, there has to be a pedagogical route”.

There was recognition of how the theme of discrimination and prejudice is constructed socially, of what the school so often contributes towards the social construction of the preconception of gender and of other social groups; and of how it needs to assume a role in the fight against discrimination, and to act on behalf of all. Schools need to reinforce the policies for fighting prejudice and respecting differences.

(4) Secondary education teachers and students: A school with a normal curriculum visited the Raul Cortez theater twice to see the film A special day, taking 400 pupils, parents and educators each time. It was a special moment. As in every session, crying and sobbing were heard in the course of the film. Six of the ten mothers who participated in the film were present at the meeting, which lead to an enthusiastic debate and a euphoric experience in which the audience, mainly comprised of young people from the primary teacher training course, was able to put questions directly to the characters in the film. The students were advised to present their questions in writing and some used the microphone to ask questions directly. The questions didn’t stop coming and it was impossible to keep up with even a tenth of what was asked. We compiled the questions, removing the repetitions and arriving at a total of 79 questions, 64.5% (49) of which were put directly to each of the mothers, personalizing the exchanges and the themes. The remaining 35.5% (27) were questions directed to the mothers as a group, with only three to the mediator. Three main themes interested the students and guided their queries: questions of gender, family and maternal care; reactions, adjustments and coexistence after diagnosis of the disability; school and prejudice. The mothers lead the debate and entered into direct exchanges with the audience.

We highlight the words of one mother, whose daughter has a serious and progressive degenerative disease. Her words are a good illustration of the impact of a severe disability on a woman’s life: “Everything is very hard, because when you are given a special child, they don’t come with an instruction manual. You don’t know how to deal with it or who to appeal to. And everything
changes in your life, right? Your family life, your personal life, your working life (...)”. As Fiamenghi Júnior and Messa put it, “The parents of disabled children live with worry all their lives, from the baby’s birth to old age, mainly due to the lack of institutions that can care for disabled people as they grow old”.

The depth and extent of this change and the impact on the woman’s life, starting with the serious condition of a child with a disability, are clear from this narrative: “Our vocabulary changes (...) But from that moment, the vocabulary becomes one of therapy, convulsion, medication and new treatment. And suddenly you stop being yourself, you’re no longer R. You’re A’s mother. And that’s how the health professionals call you for the treatment sessions: - A’s mother and there comes a time when you no longer know yourself, you don’t recognize yourself any more”. This clearly shows the change in the life of a woman, mother, wife, professional person and the importance of a support network. “The quality of the support provided by the support networks renders the experience of motherhood less arduous; and the more effective the assistance to these women, the more confident they will be in caring for the child”.

Conclusion

We saw from the words of professionals, educators and students that the film A special day impacts the public through the sensitive look at the little-known life experience of the mothers and the difficulties of the daily care, producing empathy for their hard reality and that of the disabled person and resulting in changes of perception. There are reflections on differences of gender, resilience, love, integral well-being, co-existence, respect, family, school, society and support network, from the carer’s viewpoint.

The feature-length film contrasts ten life stories, articulates various themes, perceptions and points of view, presents day-to-day situations based on life experiences and practices built, which not only clarify problems, difficulties, pain and suffering, but also point to ways of facing them, support, subjective and social tools that have been developed in the life cycle by women and families challenged by their child’s disability. By giving visibility to the voices and experiences of the mothers, in the drama of their lives, it was possible to bring to light unknown information and the emotional, social and cultural strength of the warrior women who acquire life wisdom.

The film has been referred to as a model and example of how to act with disability, due to the similarity of experiences in different cultures and societies, such as Colombia and Japan; and also for revealing aspects of family life that escape the professional eye. More than showing the richness of experience of the mothers and their children, the film reveals that these families build tools for dealing with the disability, other than the professional tools, and this constitutes an expertise to be investigated and studied. Hearing the voice of these women, mothers, wives and professionals led the post-graduates to conclude that much is to be learnt from them, and that these mothers need to be more involved as partners in health care and the building of knowledge.

Educators and primary and high school students were more struck by the family life experience, seeing the effects of the disability on the couple’s life and the overload assumed by the woman and mother. The mothers’ lack of time for themselves and how they need to receive more support called attention. The school party saw how the family could be more of a partner in the challenge of monitoring and teaching pupils with disabilities. The film “gives a nudge to schools” insofar as it shows that it is not enough to take in a special student, it is also necessary to welcome the family and support the mothers. The film prompts a change of view and posture, inviting an investment in the quality of the relations between family and school. It also give more visibility to the experiences of prejudice and discrimination, helping the school community to recognize itself as a social space that tends to reproduce stereotypes and that could work in a more conscious way to deconstruct prejudices and stigmas.

Cinema as art stimulates faster transformations in the imaginary and produces new social representations, showing itself to be a high-impact technology. It evokes in-depth debates, produces a greater approximation of social realities and life experiences and also shows the differences of gender and promotes empathy and respect for the mothers and their children. The documentary A special day gave visibility to diverse experiences in the face of deficiency, showing that as a result of the extreme care, a woman profoundly changes her life and no longer recognizes herself, and it is thus crucial to expand support and increase the network of very special women.
Collaborations

FG Cavalcante, LF Lau, GF Barbosa, DLG Berlim, NC Menezes and DC Braga participated in both the cine debates and structuring of the article. FG Cavalcante, AC Amorim and YC Amorim cooperated in production of the film, the cine debates and revision of the article.

References