Being the mother of a person with autism spectrum disorder: a study on serial representations and stigmas

Ser mãe de uma pessoa com transtorno de espectro autista: um estudo sobre representações e estigmas em séries

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Resumo: As representações midiáticas podem ser capazes de criar e reforçar estigmas e estereótipos. Tal cenário é ainda mais frequente quando se trata de grupos que são socialmente invisibilizados. Nesta pesquisa o objetivo foi analisar as representações de mães de pessoas com transtorno do espectro autista em séries. Para isso foram analisadas Atypical e Parenthood, séries de grande alcance e que são apontadas como emblemáticas no que diz respeito à representação de pessoas com transtorno do espectro autista. As análises mostraram que as tramas trazem representações que reforçam que as mães de pessoas com autismo correspondem ao estereótipo de extremamente dedicadas aos filhos, dispostas a abandonar suas vidas pessoais e profissionais, e responsáveis por manter a família unida, mesmo quando os pais dizem não conseguir lidar com o diagnóstico.

Palavras-chave: Mídia; transtorno autista; mãe; representações.

Abstract: Media representations may be able to create and reinforce stigmas and stereotypes. Such a scenario is even more frequent when it comes to groups that are socially invisible. In this research, the objective was to analyze the representations of mothers of people with autism spectrum disorder in series. For this, two series Atypical and Parenthood were analyzed, series of great reach and that are pointed out as emblematic with regard to the representation of people

1 Universidade Federal do Estado do Rio de Janeiro (UNIRIO). Rio de Janeiro, RJ, Brasil. https://orcid.org/0000-0001-6334-145XE-mail: marinadfaria@gmail.com with autistic spectrum disorder. The analysis showed that the plots bring representations that reinforce that mothers of people with autism correspond to the stereotype of being extremely dedicated to their children, willing to abandon their personal and professional lives and responsible for keeping the family together, even when the parents say they cannot cope with the diagnosis.

Keywords: Media; autistic disorder; mother; representations.

Introduction

The investigation presented here is aligned with feminist studies of communication with regard to the search to understand how media agents contribute to perpetuate gender inequality. Also aligned with what is expected in this sense, the research has an intersectional perspective (MENDES; CARTER, 2008). With these issues in focus, the objective of the present article was to analyze the representations of mothers of people with autism spectrum disorder in TV series.

For authors like Furtado (2000), communication practices are capable of building different forms of oppression in individuals. In this research, a particularly attentive look was undertaken at the possibilities of oppression that can derive from the representations of women that are mothers of people with autism spectrum disorder in series. Additionally, Scoralick's (2010) perspective that social representation in different media products is important for the development of society's identity, both on a personal and collective level, was also crucial for carrying out the analyses.

Mandes and Carter (2008) highlight the importance of analyzing various types of media products, such as soap operas, talk shows, news and movies. Although these authors do not discuss series, one can say that the basis presented by them serves perfectly for the analysis intended here, especially when they speak of the importance of showing the articulation of capitalism and patriarchy in media representations.

The focus on series is justified by authors like Silva et al. (2018), who defend the use of this type of product to seek to understand social experiences. Likewise, Pinheiro et al. (2016) draw attention to the increase in the number of series produced, in their audiences and in the complexity of the characters.

With regard to the focus on women who are mothers of people with autism, it is worth mentioning that little is discussed about media representation, stigmas and the experiences of these women. More frequent, although in insufficient quantity, are the studies that focus on the representation of people with disabilities (PwD). Such investigations

show that the representations reinforce the stigmas of the disability and the image of the disability as a difficulty experienced by a single person (AUTHOR). Since the mothers are also affected by these stigmas (GOFFMAN, 2008), it becomes relevant to develop studies of the media representation of such women who are repeatedly made invisible by the media and by society as a whole.

Representations in the Media: Stigmas and Identities

The influence that the media has on judgments and on the formation of people's opinions is the object of study of many authors. This is justified because society is marked by the existence of intervening interactions in the media context. The media seeks, most of the time, to shape behaviors that are strongly anchored in stereotypes and stigmas, which results in a lack of empathy, sensitivity and critical thinking by the receivers (TONDATO, 2011). Therefore, it is necessary to incorporate the study of media channels in order to establish an understanding of the relationships between individuals and in the very structuring of social meanings (CARVALHO JÚNIOR, 2016).

Scoralick (2010) also points out the importance and relevance of media products in society and, as a consequence, the need for all people to be represented, especially groups already stereotyped and socially marginalized. The author's main line of argument is that representation is indispensable with regard to the reproduction and achievement of rights and duties. For her, only then will it be possible to discuss stigmas.

Following other authors, Rodrigues (2008) summarizes that stigma is complex, it is a social/historical phenomenon that crosses the limits of the stigmatized and of the one who discriminates against them. For this author, it is important to understand that stigma is strategically employed: it produces and reproduces relationships and social inequalities. Equally important is to understand how media representations play a crucial role in the creation and maintenance of stigmas.

Seeking to analyze the representations in the media originates from the unease provoked by texts such as the one by Silveirinha (2021), which highlights that the world is organized between central and "exterior" subjects, and it also warns that it is important to think about this imbalance of power in which resides the notorious and historically problematic nature of representations concerning, for example, race, class, gender, sexuality, age or disability. The same author argues that the relationship between identity and representation is extremely strong.

In this research, the issues of stigma, identity and representation of gender and disability are addressed by focusing on the representations of mothers of people on the autistic spectrum in series. With regard to gender, authors such as Mendes and Cartes (2008) state that media texts contribute to the reinforcement and construction of stereotypes. Concerning the stigma of PwD, which extends to their mothers, it is easy to notice that stigmatized representations occur in scenarios and practices already socially constructed with regard to the insertion of the person with a disability in society. In other words, media products reinforce the stereotypes already socially constructed of people with disabilities, stereotypes that in no way facilitate the social inclusion of these people (BARRETO et al., 2018).

Being the Mother of a Person with a Disability: Myths, Guilt and Trajectories

Research such as that carried out by Bastos and Deslandes (2008) and Marson (2008) point out that the birth of a child with a disability represents, at least initially, a breach of expectations. For the mothers, this first moment is transmuted, most of the time, into concerns about the special cares that the child will need. With regard to the parents, it is common that they report difficulties in acceptance that generate partial or even total distancing (PINTO et al., 2016).

The relationship between mothers and children with disabilities tends to involve a feeling of guilt for having generated a child that does not correspond to the myth of the perfect child (CALVASINA et al., 2007). This myth is constantly reinforced by the media, especially

in advertisements, which show images of the perfect children with their ideal and always happy mothers, without any kind of problem (MENESES; MIRANDA, 2015). Guilt becomes ideal for maintaining patriarchal and capitalist oppression in the lives of these women who are, in the eyes of society, imperfect mothers.

One of the points to which the perfect child is expected to correspond is to be independent as soon as possible. This demand is strongly anchored in the capitalist model that emphasizes self-sufficiency (TABATABAI, 2020). Since they are dependent, in most cases on their mothers, for a longer period than expected (often for the entire lives), PwD are labeled as unproductive and incompatible with adult life. These ideas are infiltrated into the speech of the "good mother", who must give up many things in her life in order to overcome the difficulties brought about by the lack of autonomy of their sons and daughters with disabilities.

According to leading theorists focused on the theories of justice, personal dignity is closely related to independency. As a consequence, the care received by people with disabilities is seen as an attempt to achieve as much autonomy as possible. However, human beings are naturally subject to periods of dependence. Thus, Kittay (2011) proposes that instead of seeing assistance as a limitation, it can be considered as a resource in the basis of a vision of society capable of handling the inevitable dependency relationships between "unequals", ensuring a full life both for the caretaker – most often the mother, as we have seen – and for the person who is cared for.

What remains, however, is the demand for unconditional care in the quest to meet the myth of the ideal mother, which often results in maternal guilt, which will be reflected in several aspects of these women's lives (LIMA; BOTELHO, 2014). In short, the oppression of disablism centered on "perfect" or "normal" bodies and minds, and the discourse of care as a female function work in articulation so that "being the mother of a person with a disability" is a label that determines the identity of such women, stigmatizing them and shaping their social roles.

Methodological Procedures

In this research, the series *Atypical* and *Parenthood* were analyzed. These media products were chosen because they reached a large audience and are considered emblematic series with regard to the representation of people with autism spectrum disorder². In addition, these series are important for the main objective of the research because both present the families of the characters with autism in a very vivid way, especially their mothers.

The tables presented below summarize some characteristics of the two series that may be important for understanding the analyzes that will be carried out in the next section.

Table 1. Characteristics of the series Atypical

Series	Atypical
Number of seasons	4 seasons
Number of episodes	38 episodes
Release year	2017
Country	USA
Platform	Netflix
Characters with autism	Sam Gardner
Character's gender	Male
The character in the series	Sam is an autistic teenager who decides to find a girlfriend. His quest for independence sends the entire family on a journey of self-discovery.
Mother	Elsa
Family	Father – Doug Sister - Casey

Source: Elaborated by the author

² Minha Série section on the website TecMundo "5 series characters that help understanding autism". Available at: https://www.tecmundo.com.br/minha-serie/169119-5-personagens-deseries-que-ajudam-a-entender-o-autismo.htm. Accessed on: set. 7, 2021.

Table 2. Characteristics of the series Parenthood

Series	Parenthood
Number of seasons	6 seasons
Number of episodes	103 episodes
Release year	2010
Country	USA
Platform	Prime Video
Character with autism	Max Braverman
Character's gender	Male
The character in the series	Max is diagnosed early in the series and throughout the plot he faces problems with interpersonal relationships, experiences a drama with educational inclusion, but falls in love with photography, which helps him overcome problems. The series also features another character that is diagnosed with autism only as an adult. This character is not highlighted in the analysis of this research because her family (her mother) is not represented.
Mother	Kristina Braverman
Family	Father - Adam Braverman Sisters – Haddie Braverman and Nora Braverman

Source: Elaborated by the author

The series that compose the material that was analyzed in the research were watched in full, with the possibility of pauses, on streaming platforms. The methodology chosen for the analysis of the scenes in this work was content analysis. This choice was made because it allows the analysis not only of the characters' speeches, but also of the scenes as a whole (settings, costumes, interactions between the characters) (SILVA; FOSSÁ, 2015; MORAES, 1999).

To assist in the construction of the analyzes, since there was a lot of material to be organized, an Excel spreadsheet was used with variables chosen based on the literature revision. This spreadsheet was filled in with relevant information of the scenes that were chosen because of their importance for understanding the representations of mothers of people with autism. The variables observed focusing on the characters Kristina and Elsa related to issues such as: 1) job/professional activity; 2) relationship with the child; 3) relationship with other family members; and 4) performance of care functions.

To present the results, it was decided to divide the section into two parts. In the first part, a general overview is made in order to describe and analyze separately the representations of each of the two characters, mainly regarding the variables presented above. In the second part, a conversation was produced between the representations of Elsa and Kristina divided into the following topics: 1) the diagnosis and the feeling of guilt; and, 2) independence for mothers and children.

Presentation and Analysis of Results

Characterization and Analysis of the Character Elsa (Atypical)

The character Elsa is the mother of Sam, a teenager with autism, and Casey. Married to Doug, she completely takes on the tasks related to the care of the family. The character reinforces the stereotype of the mother who, when having a child with a disability, assumes full responsibility for their care (KITTAY, 2011). As pointed out by authors such as Lima and Botelho (2014), Elsa takes unconditional care of her son, gets involved in all his activities and has very little or no time for her life, independent of her son's life.

Regarding the professional activity, she also corresponds to what literature points out as very common, the mother who stops working after having a child (BALABANIS et al., 2012). Although she is a hairdresser, the character no longer exercises her profession after Sam's birth. Elsa's relationship with her son is very close and full of control mechanisms. In the series, the young man is looking for more independence, claiming his place as an adult in society. This search for his recognition as an adult is extremely uncomfortable for the mother. When she sees her son

with more autonomy, the character doesn't even know what to do with her free time.

Elsa's relationship with her daughter Casey is marked by the mother's demand that her daughter be responsible for her brother. At a certain point in the plot, there are many fights between the two, as Casey starts to demand that her life be independent of her brother's life. The attribution of responsibility to the sisters, with regard to the care of the brother or sister with a disability, is also something mentioned in academic research that interviewed families of people with disabilities (PINTO, 2011).

As for the relationship between Elsa and her husband, it is very conflicted at the beginning; the couple even separates. It is known that Doug left home when Sam was small because, according to him, he was not able to deal with his son's disability. This situation and the very limited involvement of the father with his son are important points for the relationship between Doug and Elsa. The relationship between these two characters perfectly illustrates what happens to many couples who have children with disabilities. The literature shows that it is common for the father to distance himself from the child and the family as a whole, leaving all responsibilities to the mother (PINTO et al., 2016). It is worth mentioning that in this plot the father leaves home, leaves Elsa with the children and then she gets involved with another man and is extremely crucified for it. There is an explicit judgment that she is the only one to blame for the separation because she cheated. Throughout the series, Elsa and Doug reconcile and reinforce the social representation that everything that the man does, especially not taking care of his disabled son, must be forgotten by the woman in order to keep the family together.

At the end of the plot, Sam acquires much more independence and gets closer to his father. Elsa, however, never accepts her son's greater freedom and suffers when she sees that he is more independent. The entire series reinforces the view of the mother as a controller who does not want her son to have his own life. This type of representation

is extremely harmful and puts the blame for the social exclusion experienced by people with disabilities on their mothers, in addition to reducing the responsibility of the father and society as a whole.

Characterization of the Character Kristina (Parenthood)

The character Kristina is the mother of Max, a boy who is diagnosed with autism early in the plot, and she is also Haddie and Nora's mother. Even though the father, Adam, plays an active role in Max's life, in many episodes it is clear that the burden is all on Kristina, because she is the one who does all the main day-to-day care tasks. That is, although Adam does not abandon his child after the diagnosis, which is very common (KITTAY, 2011), the responsibility for care is almost exclusively on Kristina. At some points in the plot, we even get the impression that Kristina should be thankful for having a husband who did not abandon the family.

The character's story is very representative of the dichotomy between public and private space – which is highlighted in academic literature (CANO, 2016) – since she did not work at the beginning of the plot. Later, the spectator gets to know that before her child was born, she used to work on political campaigns. Towards the end of the plot, she herself runs for political office. During the episodes when the character decides to run and campaign, there are many scenes in which other characters question how she would be able to conciliate her public and political life with her attributions as the mother of an atypical child. This discussion about the presence of such women in public and power spaces is urgent and fundamental in order to question the social exclusion of women who are mothers of people with disabilities.

Still with regard to the professional aspect, Kristina loses the elections and ends up opening a school for children with autism spectrum disorder. At this point, the plot gets very close to the life stories of many women who change their professional paths in order to provide better access to education for their children (PINTO, 2011). It is important to mention that it can be very hard to believe that solutions like the one

found by the character are viable for most families. Logically, opening a school is something that demands a lot of effort, knowledge and financial resources that are not within the reach of almost any family. Additionally, it is extremely complicated to think that the flaws in the educational system, which is, in most cases, inadequate for children and young people with disabilities, should be corrected with individual solutions. A good and accessible education for all should be a commitment of the public authorities and not the responsibility of each family and/or specific actions.

Kristina's relationship with her son is extremely close and based on the attempt to provide him with independence. An important moment in the plot is when a character, Hank, is diagnosed with autism when he is already an adult. For Kristina, knowing that Hank has a profession (photographer) and an independent life is very comforting, it gives her hope about Max's future.

In addition to Max, Kristina has two daughters. Her relationship with the older one, Haddie, is totally marked by demands that the teenager should be responsible for taking care of her brother. Many scenes show clashes between them since the girl wants to go to study in a different town and have a life less tied to Max. Kristina behaves with Haddie as if she had to prepare her to take over the responsibilities for her brother, a behavior that is often presented by mothers of people with disabilities (PINTO, 2011). The other daughter, Nora, is born during the plot and there is a suspicion, which is not confirmed in the end, that she would also be within the autistic spectrum.

Cross Reflections on Kristina and Elsa

The Diagnosis and the Feeling of Guilt

The literature on people with disabilities points out that the moment of the diagnosis is usually a turning point for families, especially for mothers who often end up blaming themselves for their children's disabilities (CRISOSTOMO et al., 2019). The character Kristina, unlike Elsa who begins the series with her adult son already diagnosed, experiences the discovery of her son's diagnosis in the plot. As pointed out in the literature (BASTOS; DESLANDES, 2008; MARSON, 2008), the character is extremely impacted by the news and seeks explanations that include blaming her for her son's disability. At the moment of the diagnosis she asks the doctor: "Doctor, please be honest, am I to blame for him being like this? Could I have done something different? And now, what should I do?"

Kristina's last question, in the speech transcribed above, shows that she intends to take on the responsibility of doing whatever is required for her son to have a good quality of life. This sense of responsibility is linked to the myth of conditional love and the perfect mother, who can give up anything for her child (CALVASINA et al., 2007). Even though the series does not portray the moment of Sam's diagnosis, there are scenes in which the characters talk about this past moment. In one of these scenes, Casey (Sam's sister) questions her father about his absence for eight months after Sam was diagnosed. The father says he is not proud of having acted this way and talks about the difficulties related to the diagnosis. In the same scene, Doug says he is very proud of the way his wife began to dedicate herself exclusively to taking care of Sam. He adds that his wife was wonderful and that he couldn't accept his son's diagnosis, unlike Elsa who felt relieved, since she had already noticed that Sam presented atypical behaviors and felt anguished for not knowing the motive. All the discussion between Doug and Casey has very strong points of contact with what actually takes place in many families. The diagnosis brings great anxiety and frustration for fathers and mothers. However, the way of dealing with the situation is completely different since fathers are socially allowed/accepted the option of not being able to cope, moving away, taking their time. The mothers, on the other hand, are compelled to quickly accept and to start acting in order to provide better living conditions for their children (PINTO et al., 2016).

This need to quickly deal with the diagnosis is very well illustrated in the speech of Elsa, Sam's mother, which is reproduces below:

I think it's a relief, actually. Now we know, we can act. I was reading about noise canceling headphones, they help a lot in situations where he feels bewildered. It's such a simple idea, but I would never have thought of it. It makes so much sense. I'm going to the store to buy a pair, and there are also other things, we can make some changes.

The feeling of guilt for not having produced a perfect son, which is pointed out in the literature (CALVASINA et al., 2007), appears in different ways in the characterization of each one of the characters. Elsa corresponds to the most frequent characterization: she blames herself for her son's condition and, largely because of this feeling she dedicates her life to taking care of the boy. At the time the series takes place, Sam is already an adult and it is only then that the mother begins to allow herself to have a life minimally detached from her son.

The character Kristina, on the other hand, does not demonstrate that she feels guilty in most of the plot. However, when it is discovered that her niece is gifted, the character questions herself about her son's condition. At this moment, a distance is created between Kristina and her niece's mother, Kristina's husband's sister, based, even if in a veiled way, on a hierarchy of someone who produced a child with a disability and someone who generated a gifted one.

Independence for Mothers and Children

Capitalism proclaims that only someone who is independent is a full adult (TABATABAI, 2020). Therefore, and because we are totally inserted in the capitalist logic, the pursuit of independence has a central place when we discuss issues related to disabilities.

In the plot of Atypical, the search for independence is central. Sam works and in his work environment, in an electronics store, he has some autonomy. However, when he wants to leave his home, Elsa, his mother, puts up several barriers and in many scenes she says things like: "Do you

think you can live by yourself? Have an independent life? You can't. You'll never be fully independent".

On the other hand, Kristina, Max's mother, shows that she expects her son to be fully independent when he becomes an adult and hopes that this will happen if the boy manages to have a profession: "I want him to grow up and be independent. That's why I want him to discover a profession that he likes and to follow it. Photography may be an option".

For both characters, Kristina and Elsa, the perspective of their sons' lack of independence in the long run is very uncomfortable. The two talk about feeling that they can not die. This feeling had already been portrayed in the literature as being frequent for mothers of PwD (PINTO, 2011). In Kristina's case, a very significant part of the plot is when she finds out she has breast cancer. At this moment, her biggest fear becomes that her son will have no one to take care of him in case she dies

With regard to her own independence, the character Elsa experiences a life change as she begins to realize that her son is no longer so dependent on her. The series shows this transformation in the life of the character, who gradually stops seeing herself only as a mother and rediscovers herself as a woman.

Kristina appears from the beginning as more independent, if compared to Elsa, but when the couple have another daughter, Nora, and there is a suspicion that she also has autism, the mother is certain that she will never again have her life independent of her children.

Final Considerations

Regarding the initial commitment which was assumed to take a close look at the possibilities of oppression that may arise from the representations of women who are mothers of people with autism spectrum disorder, we can state that both series have a great possibility of reinforcing stereotypes about these women. In the analyzes, it was possible to identify that the characterizations of the characters are widely permeated by the oppression of capitalism and patriarchy.

An example of the presence of this articulated oppression is the representation of Kristina and Elsa as the only/main caregivers of their children. Naturalizing such a configuration in media representations can be extremely powerful in reinforcing that the responsibility for care lays with women, in this case mothers. This accountability frees the father from many issues and removes the woman from public spaces, including work.

In short, the representations analyzed reinforce that mothers of people with autism correspond to the stereotype of being extremely dedicated to their children, willing to give up their personal and professional lives and to be responsible for keeping the family together, even when the fathers say that they are not able to deal with the diagnosis. This characterization is obviously very harmful for these women, who are compelled to cancel their desires in order to become an extension of their children's needs. Therefore, there is an unconditional search to correspond to the standards of perfect mothers proclaimed by patriarchy and capitalism.

As a suggestion for future study, it could be very fruitful to carry out studies on the media representation of sisters of people with disabilities. In the two plots analyzed, these characters were very rich in important issues to be analyzed, such as, for example, the perspective of having their lives always linked to those of their brothers.

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