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"We, mothers of autistic people": between knowledge of the experience and collective memories in videos on YouTube

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Abstract *This paper results from research that analyzed the narratives of mothers of autistic children about their experiences with their children, produced and shared by them through videos on YouTube. We used a qualitative methodology to debate the logic and meanings attributed to illness, health, motherhood, and childcare, towards a narrative reconstruction produced by us researchers. We observed that these women spoke primarily about their experiences as mothers of autistic children and directly addressed the emotional difficulties of having a child with autism, such as mourning the ideal child promoted by the diagnosis and the construction of care for an autistic child. Through the videos, the mothers form an identification group based on the premise that they lived everyday experiences, generating significant value and becoming an existential capital. Talking about such experiences in public and far-reaching spaces like YouTube produces, among other things, collective memories that develop a caring community. We understand that the individual story reported and produced in the videos can emotionally and pragmatically help others with a similar experience, re-inhabiting daily life.*

Key words *Autism, Motherhood, Social media, Narrative*

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Introduction

This paper is an excerpt from research that analyzed the narratives of mothers of autistic children about their experiences with their children, shared through videos on YouTube[1]. The increasing importance of the Internet in people's lives, ranging from interpersonal relationships to economic sectors[2,3], and the significant contribution of digital social networks to build a public sense of health[4] indicate the relevance of this work. Furthermore, it is not uncommon for families of autistic individuals to express, during clinical care, that information shared by families of autistic children on the Internet helps them in the daily care of their children[4,5]. The intention of listening to mothers arose from the interest in analyzing what was said about autism by people who are not specialists – such as doctors and therapists –; that is, people with no cultural capital[6] to talk about autism, but who had the everyday experience of dealing with autistic children.

Methodological aspects

The survey was conducted on the digital video sharing platform YouTube, as there are several mentions about its use by parents in research on parenting and autism[5]. Also, YouTube is a collaborative content platform, the most extensive online video publishing and display site[7,8]. Its popularity mainly stems from the technical features that allow practical and simple sharing. Much of the content available on the platform is produced by common people[9].

The mothers who shared the analyzed videos did so in public mode and are aware that such content is available for access to all platform users. Therefore, based on Resolution N° 510/2016, there was no need to submit the survey to the CEP/CONEP system. However, we protected the identity of those who participated in the videos analyzed in this research.

The platform's main features relevant to our research were the player, in which the video is displayed; the comments section, in which users and producers can text messages; and channels, in which all videos shared by a given user are organized. We analyzed the images and narratives produced in these spaces and the social interactions that took place there.

We employed a qualitative methodology as our interest was to investigate the narratives produced by the mothers of children with autism. It allowed us to debate the rationale and meanings attributed to disease, health, motherhood, and childcare. We followed the path pointed out by Castellanos[10] towards a narrative reconstruction we produced. This narrative is the second level of interpretation, where the first level is the narrative of the researched subject – in the case of this research, the mothers who produced the videos. We selected this method because we also understand that videos shared on YouTube do not expose, in themselves, the "truth" on the researched subject.

We opted for the strategy commonly used on the platform to access the content of interest[11] to select the videos with greater capillarity among parents of autistic children, namely, search engine and keywords. Data were collected in May 2019. We searched for words "*autistic child*" on the platform and applied the filter "sort by" in the option "view count", and selected for screening the first 50 most viewed videos. Finally, we chose for analysis those produced by family members, totaling 18 videos. We systematized the analysis by opening a text file for each video and placing descriptive information, transcripts of video excerpts, comments, and simultaneously making associations with theories and interpretations that emerged during each video's viewing.

Results and discussion

The analyzed videos totaled 3,656,796 views and had different lengths – the longest was 19min55s and the shortest 2min19s. They were published in 2018 (6), 2017 (6), 2016 (2), 2013 (2), and 2011 (2). No video was produced by mothers about their autistic children in 2019, probably because the survey was conducted earlier in the year. We identified 3,875 comments distributed into eight videos – the rest had no comments, as the section had been "disabled" by the channels.

Mothers made all the videos, and some of them were responsible for more than one video. Thus, we identified videos produced by the same person and arrived at ten channels that were analyzed. Among them, seven had less than 20,000 registered users, few videos on the channel or irregular publications, and three had an average amount of 100,000 subscribed users and regular publications. Most of these channels (7) talk about motherhood exclusively in the autism reality and the others about motherhood in general, including the experience with an autistic child.

Concerning verbal and visual languages used, the videos are similar to others on YouTube.

These videos invite users to subscribe to the channel, "like" the video and share it with friends. Most mothers appear alone indoors. Their statements are organized and clear, showing that they follow some script and preparation, and mothers are dressed casually and made up. This group of videos can be described as testimonial[2] – those in which individuals provide their testimony as if they were talking to the viewer – or didactic[2] – those with an informative narrative to show a specific aspect of an issue.

A handful of videos show the children and their "evolutions". These, in general, do not have direct statements, only images and texts showing something learned, apparently, without prior production. The audio, image, and editing quality are visibly amateurish, and the videos seem to have been shot with smartphones.

Information about the mothers was insufficient, which hindered outlining an accurate profile of them. However, we identified that they were primarily young adults and probably belonged to the middle class through their clothing, physical space, and language. When we investigated other videos on the channel, the scarce information available spoke about where they lived and the type of health network they accessed. For example, three families lived abroad (the U.S. and Europe), and the other seven lived in the Southeast of Brazil. Two families used the SUS to treat their children, two attended mixed services (partially financed by the government), and six underwent private treatments.

The approximate age of the children ranged between three and seven years old, and a mother talks about her (autistic) adult child in only one video. Furthermore, most of them are male, with only a girl. We found that mothers describe their children by categorizing them into "degrees of autism". Most call their children "moderately autistic", others "mildly autistic". The only adult has "severe autism", and one mother said she did not yet know "the degree".

As indicated, we searched for videos produced by relatives of autistic people about this condition, and we realized that mothers are the primary video producers. However, the search for narratives about autism resulted in videos that addressed, in the foreground, the changes in the lives of mothers from the birth of their child and, more specifically, after the child's diagnosis. The videos brought a little discussion about autism as a nosological entity and highlighted autism through the experience of motherhood with these children.

Even when the video indicated that it would address autism, describing it from the stages of development and other characterizations, most dealt primarily with how mothers experience and experienced these processes. As an example, we have a video in which mother and child appear, and the mother says: "*Today Mom is going to talk about you. Can Mom talk about you?*" and she goes on to narrate the trajectory and feelings she experienced in her son's diagnostic definition and how her daily life changed after this "discovery".

We observed that mothers identify themselves as "mothers of autistic children" based on the belief that their experiences were similar to those of other mothers with autistic children, mainly based on the assigned diagnosis. Also, we identified that the mothers of the analyzed videos knew from the experience described as an existential capital[12], pointing to a value/capital built from collective formations, based on the identification of personal experiences. In this context, some of these mothers identify that only those who experience the situation – having an autistic child – can understand it and share a shared universe.

Based on these perceptions, we divided our analysis into two major, interconnected themes: "The 'Autistic's mother': experiences around the diagnosis" and "Construction of the common between the knowledge of experience and shared memories".

The "Autistic's mother": experiences around the diagnosis

We saw in the reports of the videos that mothers are established as mothers from their child's autism, and it is difficult to see themselves only as mothers: they are mothers of autistic children. Presenting themselves publicly through the symbolic references of their children was observed in other studies[13,14], which paved the way for us to understand the identity that emerges from the image of the self, consisting of the mother-child dyad.

Some mothers identify themselves as "blue mothers", referring to the color usually employed to represent autism[4,15], as in the statement of a video: *Our mother's life and, mainly, (she stops and laughs and says in a tone of confession), I was going to say little blue mother (back to normal tone)*. By incorporating blue or the quality of "autistic" into the motherhood experience simultaneously, the mothers in the videos differentiate themselves from other mothers who are not part of this group and shed light on the process of becoming a mother from the specificity of their children. This is how a mother writes in the description of her video: *Being a mother of an autistic child is not easy... only those who experience this daily struggle know...*.

From the narratives, we identified that the entry of mothers into the reality of autism is more expressive based on their children's diagnosis. Rosemberg[16] argues that being diagnosed articulates the individual experience with the social and is a rite of passage from uncertainty to a structured narrative. Mothers narrate a paradoxical relationship with the diagnosis, as while indicating relief for making sense of the differences observed in their children's behavior, they find themselves in a complex and unknown social place. If the anguish emerged from the fact of "not knowing what is happening" before, it now emerges from not knowing what the future will be and the need to assign a new meaning to who one's child.

Mothers describe that something "new" is imposed when the medical diagnosis is given. Expressions such as "*the penny has dropped*", "*a thump*", reports of crying, and a feeling of helplessness are common among them. Such descriptions are in line with what Moreira et al.[17] analyzed about the experience of family members of children and adolescents with rare diseases, marked by the "scare" of the diagnosis.

A "before and after" is established in the mothers' history, an experience that can be read as a "biographical rupture"[18]. The symbolic bases, material and emotional resources on which the person's life was structured until then, are significantly shaken. Thus, an immersion in a new world begins, permeated by experiences arising from their children's condition and the related subjective aspects. For the mothers in the analyzed videos, the "before" is articulated with the ideals and expectations built by the mother vis-à-vis her baby, which start to falter from the "intuition" that her child has "something wrong". The "after", in turn, stems from the medical confirmation of the diagnosis, setting the mother in a new universe, as new meetings are built with doctors, the health system, medical language, technical terms, and the very ghosts.

The moment from realizing that something is different with the child to getting a diagnosis is often described as "*fighting for the diagnosis*", understood as something to be fought for. The path taken to "*achieve*" the diagnosis is long and, at times, traversed by complaints of professionals' technical incapacity. On the one hand is the perception of mothers that there is "*something wrong*" and, on the other, a position of experts that says "*it is just a delay*", "*he just has a speech delay*", or "*you're looking out for disease for your son*".

The "*fight*" is for the differences that mothers identify in their children to be recognized as a biomedical signifier, going from "*something wrong*" to autism. As we can see in one of the comments: *The psychologist told me that I need therapy and that I am looking out for illness for my son; she only sees him once a week, and I find him strange and different since he was a baby...* Or: *Our fight is hard! Getting a diagnosis and a doctor to diagnose; getting treatment because everyone thinks he doesn't need it. Then we will have to convince others that our child is autistic. It's very tiring.*

Although all children are different from the fantasies of their mothers and fathers, the subjective process of matching what was fantasized to the real child is especially delicate in the case of children with developmental difficulties[19]. In parental projections, one does not expect that anything will interfere with the child's performance. This process is represented in the following statement in one of the videos: *...nobody gets pregnant wanting to have a disabled child. So, it's a huge shock. You idealize a child in your head, set expectations, already imagine moments with that child and a lifetime for that little being that is inside your belly*.

Some accounts express the "loss of a child", indicating the mourning of the ideal child when that child that was imagined no longer exists. A mother reports about the moment when the doctor confirmed the diagnosis: *It was as if all my dreams and expectations had been ripped from me. As if they had taken [child's name] from me, taken him away and given me another one, and said 'take this one'!*

Considering that motherhood is a construction that involves aspects of women's psychic uniqueness, traversed by sociocultural aspects, women giving birth to a baby should take the subjective place of a mother[20]. Cultural insignia, such as the idealization of motherhood or the ideal of shared normality, shape the way of experiencing being a mother and, in this sense, women with autistic children can significantly affect the plans for the future and how they value their families, including their identity as mothers. This is illustrated, for example, in a video in which the mother reports that, upon understanding that her daughter with autism would be different from her ideals and expectations, she would then need to "be another mother for her".

The idealization of motherhood presupposes the "ideal mother" and the "ideal child". With the child's development, the idealization built about it is confronted with the features of the actual child. A gradual change occurs in the psychic representation of mothers regarding the child, and a process of adjustment takes place on how it will act in its psychic economy, as one mother expressed: *I am the mother of [daughter's name], and as a mother, I don't want anything to happen to my daughter. I wanted her to be born without any difficulty, commitment, and diagnosis*.

While the mothers of autistic children are not a homogeneous group – as they build and attribute their meanings to their children's autism and express different ways of addressing the diagnosis –, the personal impact of the diagnosis resonates similarly among them, insofar as it is closely linked to how autism is socially represented and how public narratives about the place of mothers and fathers are constructed. It is necessary to self-reinvent, reorganize family dynamics and, above all, reconfigure what is considered "normal". A new mother is inaugurated in the encounter with the diagnosis of a child, with new plans and who starts to understand herself from the identity of "the mother of an autistic child".

Two main areas deserve to be highlighted in this scenario of construction of "autistic motherhood". The first refers to the specificities of the – common – experiences of mothers of autistic children, especially those linked to the care of their children. The second scope is interconnected with the first and refers to constructing the feeling of identity – "the mother of an autistic person". A group idea is built as mothers self-identify in this way, which will be further explored in the following topic.

Mothers who accept their children's differences, despite their broken mothering expectations, subjectively build new relationships with them to make the experience of motherhood possible. Taking care of an autistic child is a complex task permeated by contradictions. However, it is also the dealing with them in their daily lives that allows building the subjective place of "mothers of autistic children". Addressing the issue in daily life means monitoring the "atypical" development of own children, learning from them that the waiting time "for the milestones" (of development) is another and communication is different.

Dealing daily with the children's eccentricities is also experiencing a frequently violent daily life. These children and their families live in an environment that is not prepared for their ways of being in life. They pick up the effects of stigma and prejudice arising from their atypical performances. This is reflected by a mother in her video: *Much therapy in someone's life to overcome the fact that you are a neuroatypical person living in a world designed for neurotypicals*. She recognizes the prejudice manifested in indiscreet looks, motivated by the repulsion to difference and social exclusion producers. This mother chooses to name the difference, referring to the neurodiversity movement that considers autism not as a disease that must be treated or cured but as a manifestation of human differences[21]. Another mother talks about the complaints that the school constantly made about her son's behavior: *(...) he didn't stay quiet at school; he kept his hands over his ear. (...) there was a complaint every day in the classroom before; they complained every day that [son's name] did not sit down, made a mess, did this, did that...*

The lack of acceptance of autistic differences, indiscreet looks, and the most diverse prejudiced situations tend to cause mothers to avoid social interaction[22]. This is an essential point of identification among mothers and mobilizes them to come together and help other mothers. The mothers in the videos self-identify as mothers who help and are helped and associate "showing everyday life" with "help". A video, whose content is the child's experience with some medication, reporting the effects and the decision process on whether to medicate him or not, contains the following comment: *You helped us, mothers of autistic children, a lot*.

Talking about lived experiences means, in other terms, narrating individual memories about the daily life with an autistic child. However, when these memories shared by the videos are accessed by other mothers whose experiences are similar, we witness the construction of robust identifications, as illustrated by the statement of a mother who, when narrating about a daily difficulty, interrupts her explanations to say: *Mothers with autistic children will know what I'm talking about*. Also, the mothers in the videos constantly use the first-person plural to narrate their experiences, *we, mothers of autistic children*.

With each video produced, seen, and reviewed, each comment read, reread, answered, these mothers inhabit, and re-inhabit everyday life[23]. Although individual experiences are narrated, there is something of the common order that enables the mothers of autistic children to self-identify as such, in the register of social identity, as Pollak[24] points out. Based on shared experiences and memories, a social identity is built and accumulates experiences and reinforces the community spirit in the social sphere.

Construction of the common between the knowledge of experience and shared memories

We saw that there are common experiences that allow a strong identification between the mothers of autistic children and, thus, the construction of the "mother of autistic children". Pollak[24] argues that identity is the image we build about ourselves for ourselves and others. Social identity is articulated with collective and individual memories, and both underpin the notion of unity and coherence of the individual. Another fundamental aspect is that identity is built regarding the other's perspective: "Identity construction is something produced concerning others, the criteria of acceptability, admissibility, credibility, and which is made through direct negotiation with others"[24] (p. 204). Memories and identities are not essences or something immutable; on the contrary, they are constructions that dialogue with the disputes and values at stake in a given sociocultural context[24].

Besides the identification among mothers, we observed shared memories that support the idea of community and create alliances. One way to establish an alliance between mothers is sharing their daily experiences, mainly because mothers with children with developmental challenges, in general, do not have people in their daily lives with similar experiences[25]. As a mother tells us: *Here, I can't hold people's hands. I can't hug, because I receive many messages here. But I can help somehow with the videos and the activities I post, such as my daily life (...).*

In a different scenario, narrated by Vianna and Farias[13], about the movement of mothers of police violence victims, the authors observed the construction of a sense of collectivity based on the sharing of personal pain. The paradigmatic scene they brought was of a public assembly in which a mother is authorized to speak for what she understands to be her group. As they refer, *in the name of a community that is at the same time vague, but identifiable in a more or less concrete way*[13] (p. 82), the mother narrates the pain of losing her child but says "we, mothers" when she speaks publicly about her suffering.

Challenging everyday experiences require mothers to rebuild their daily relationships; that is, creating ways to re-inhabit everyday life, determining these women's subjectivities. From this perspective, daily life means a unit that finds its concrete expression in the communities to which the mothers belong, in which repertoires of statements and actions are defined, and the sociocultural resources with which they face adversity are found. Furthermore, daily actions and hospitality gestures, morality in recording the common, the threads woven into the fabric of life, says Das[26], promote satisfaction and make reparation possible. About this, we have a mother who says goodbye in her video saying that "*there is a lot to share*", making the following reservation: *I'm not a therapist, I'm not a speech therapist, I'm just a mother wanting to share things like a mother to you.*

In the wake of Pollak[24], we understand that, while unique – as they are perceptions of lived reality –, the analyzed narratives are a collective and social phenomenon insofar as the scenarios that underpin daily life or are created in the collective imagination shape the memories that make up the individual experiences of mothers. Individual memories, when incorporated into a group, are traversed by collective memories inherited by socialization. A group can be understood as the society in which they live, but also the small groups to which the mothers belong, such as, for example, the YouTube channel and the interactions that take place there. In this sense, YouTube videos can be read as a locus of expression for experiences and a locus of socialization and production of new memories.

According to Pollak[24], events, characters, and places are the criteria that form collective and individual memories and underpin social identity. Events can be experienced personally, in the individual's daily life, and "by association", that is, by a group to which the person feels they belong and, while not being personally experienced by the individual, they gain significant strength in the individual imagination. Thus, memory consists of concretely lived but also some type of inherited memory. People and characters who contribute to memory creation can also be visited directly or by association. Besides the people met throughout life that underpin the settings of interpersonal relationships, Pollak[24] refers to the characters visited "by association", who become almost acquaintances, and historically or politically recognized figures. The same can be said about places, which are part of personal memories or public memory.

The mothers who produced the videos have daily experiences with their children, but they also experience events "by association" when interacting with other mothers. Thus, the everyday contents transmitted by the videos are the memories of those who produce but also of those who watch them. The identification vis-à-vis the events can be seen in the constant use of the first-person of the plural also in the comments on the published videos, besides statements pointing out the similarity of what was experienced, such as *God bless you! I thought I was the only one experiencing this: you are great and congratulations*" and "*Amazing! The same thing happened to me!*

Mothers' elaborations on autism, autistic motherhood, and the social identity "mother of an autistic child" form the basis for mothers to identify that they possess the knowledge to transmit, be recognized, and legitimized by other mothers. At stake here is a capital that encompasses the existential variable. It directly refers to the daily life and the vicissitudes of being a mother of an autistic child, and experience is a powerful differentiation principle between those living with the condition and those who do not. In this sense, their narrative is a way of transmitting that informs and builds ways of being in the world (with the autistic child).

What is at stake is who has the necessary knowledge to talk about the autistic condition beyond the specialists – doctors, mostly. Mothers have a prominent place among those who know about their children's condition, insofar as there is a value offered to the individual experience that translates into the recognition of knowledge produced from experience. According to Nunes[4], it is common for family associations to offer courses, educational activities, and lectures on autism and, despite calling on "experts" in the fields of law, pedagogy and psychology, they provide people with an important place to talk to family members and associates, sharing their experiences and opinions in these spaces.

While heterogeneous concerning the foundation and characteristics of the families, Rios[27] believes that a constant feature of most associations is to legitimize their actions through a combination of actions based on evidence supported by the knowledge of experience. Recognizing mothers' knowledge from their experiences with their children goes against the modern perspective that mothers should adhere to the scientific guidelines transmitted by doctors to take care of their children[28], without considering the specificities of the children, the mothers, and the relationship established in the dyad.

Larrosa argues that the knowledge of experience has an *existential quality; that is, its relationship with existence, with the singular and concrete life of a singular and concrete existent*[29] (p. 27). It is not about being well informed – although they often are –, but about being touched by their children's condition, and from that, producing knowledge. Thus, if, on the one hand, it is about a particular, subjective, and contingent knowledge, marked by unique experiences, on the other hand, the experiences have meeting points, paths traversing similar territories. Mothers share something in "common": their "struggles", feelings, daily challenges, and the construction of motherhood within the reality of autism.

The blurred differences in favor of the common are established in one of its dimensions due to the establishment of an existential capital arising from the understanding that only those who experience a particular situation can understand it and, from that, narrate, transmit, and share. The strength of this idea creates a familiar universe, a universe of "skilled" people to talk about a certain topic[12]. This is how Vianna and Farias[13] also present when they indicate that, despite being grateful for the support and solidarity of other people who have not "lived it in the skin", mothers make it clear that only those who have the unique experience of having lost a child to police violence know what it is.

The act of narrating enables mothers to organize their experiences and reconstruct their daily lives while producing collective memories, enabling the development of an affective community. According to Caldas[30], from Halbwachs' perspective, the formation of shared memory occurs, above all, through affective affinities and joint trajectories and, thus, it presupposes an affective community.

The affective gains also structure the narrative construction of personal experiences and the sharing of analyzed videos. This is what a mother tells us about her encounter with another "autistic mother" on the social network: *I began to understand that what I was going through could be shared; it could be shared, and what [the woman's name] did for me... [the woman's name] saved me. I can do it for other people.* The affective adherence to the group is permeated by the idea that all experienced something in common, for example, the pain arising from their children's experience of difference.

Therefore, constructing a common and affective community provides a critical social place for the mothers in the videos – that of mothers of autistic children. If, on the one hand, mothers constantly deal with situations of prejudice and violence due to the difference between their autistic child and the world, on the other hand, their experiences as knowledge are recognized.

Another critical dimension of publicizing unique experiences is the possibility of the report reaching other people with the same experience and producing a network of sociability, albeit digital, from this encounter. The individual story reported and produced in the videos can emotionally and pragmatically help others with a similar experience, re-inhabiting daily life[23].

Final considerations

As indicated, the women in the analyzed videos spoke primarily about their experiences as mothers of autistic children and, primarily, in a confessional tone, addressing the emotional difficulties of having an autistic child, such as the mourning of the ideal child promoted by the diagnosis and the construction of the care for an autistic child.

We identified that the videos that prioritize the experience of being a mother of an autistic child, both in their pragmatic (how to take care of the child) and reflective dimension (how to elaborate bad feelings), received more views than the videos that reflect on what autism is or that promote discussions about public policies or the best therapy. Given the experience of having an autistic child, we understand that mothers who seek the videos prioritize discussions about something that directly affects them in their daily lives: references to how other mothers deal with the difficulties emerging from this reality and willingness to share their experiences with the community.

Therefore, the analyzed videos show, above all, women's narratives about what it is to be a mother of an autistic person, their experiences, how they experienced the crossing of autism in their daily lives, how was the subjective mobilization of the diagnosis of their children produced, affecting the exercise of motherhood and show us the construction of identifications between mothers who produce videos and mothers who watch and comment on them.

Indeed, the experience of motherhood in the context of autism is not exclusively addressed in the types of videos analyzed, as other sources show such experiences, such as autobiographical books, documentaries, and movies. We understand that such narratives shared on YouTube have affected how mothers produce the videos and how the audience perceives them. The videos on YouTube have an ethos that dialogues with the platform's logic by calling for the hyperexposure of "ordinary" people, which builds an image in front of the audience that they are real mothers with real experiences. We can observe the production of an "authenticity aura"[31] in these contents, which is quite significant on it while not exclusive to this platform. One of the resources is the exhibition of intimate and, at first, private moments, either through the insertion of photos or footage.

However, it is essential to point out that all participants were white and probably middle-class women, and we know that socioeconomic and racial factors mark the experience of having an autistic child differently. In one of their differential aspects, social class and skin color directly influence access to treatment for the child and the quality of care, and determine, to a certain extent, the circulation spaces in the city and meetings with peers. In this sense, other studies should analyze the reported experiences of black mothers with autistic children.

Collaborations

BMS Freitas and P Gaudenzi were responsible for all stages of article production.

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