DIGITAL PLATFORMS AND TURNER SYNDROME PATIENTS: the mediatization of health

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IV **Seminário** Internacional de Pesquisas em **Midiatização** e Processos Sociais

Turner Syndrome

- Chromosomal disorder;
- Occurs in 1 in every 2000 live female births;
- The patient has an alteration in the number of chromosomes (in 45% of the cases the karyotype is 45, X);
- The syndrome can cause physical, systemic and cognitive alterations (ex: short stature, kidney and heart issues, non-verbal learning disorder, infertility).

About the research...

Objective: To investigate how the communicational experiences (appropriations, interactions and media products) of Turner Syndrome patients and their relatives on digital platforms show the emergence of mediatization logics

- The self elaboration of new meanings about Turner Syndrome and about their own life, through communication
- The emergence and elaboration of different relationships that exists on digital platforms

Mediatization

The boundaries of social fields are not well delimitated anymore, representing new possibilities to subjects that are not normally addressed by the media to be visible in others spaces, for instance, digital platforms.

Health Communication

On mediatization society the choices are in the hands of patients. Furthermore, they interact with people who share the same life experiences and produce knowledge, what could be a source of information for the ones who are looking for data about an specific illness.

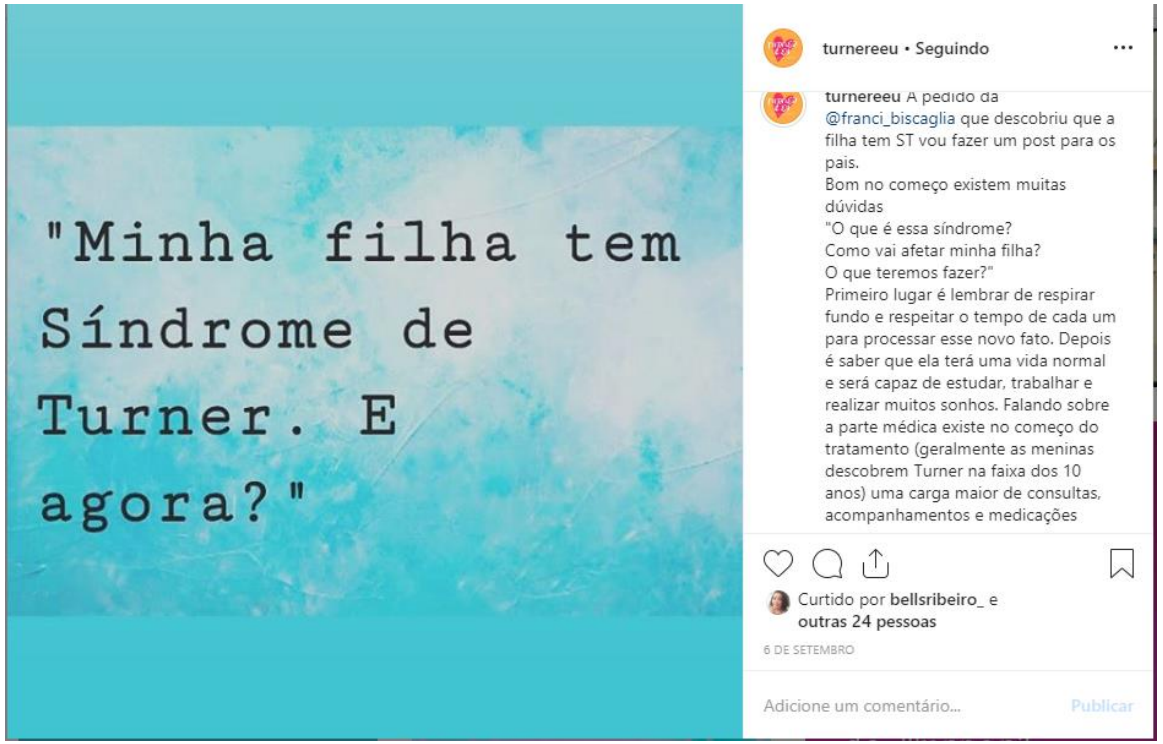
Turner Syndrome Global Alliance (TSGA)





- The posts focus on characteristics, diagnostic, awareness, treatment and motivational quotes;
- It shows a positive side of Turner Syndrome (girl and women in the picture, tone of the posts);
- The information available does not talk about details, they generalize some aspects of the syndrome;
- The organization does not interact with the followers, which shows a distance from the families and patients who comment or share the posts;
- The page does not have a personal purpose;
- The speech uses medical expressions without explaining them – the page is for the ones who do not have much information and want to understand the syndrome;
- The subtitles with short and direct sentences;
- The page aims to reach girls and women with TS and their families;
- Patients and people related to them have more access to information that were previously difficult to discover.

Turner & Eu


"Minha filha tem Síndrome de Turner. E agora?"
turnereeu • Seguindo
turnereeu A pedido da @franci_biscaglia que descobriu que a filha tem ST vou fazer um post para os pais.
Bom no começo existem muitas dúvidas
"O que é essa síndrome?
Como vai afetar minha filha?
O que teremos fazer?"
Primeiro lugar é lembrar de respirar fundo e respeitar o tempo de cada um para processar esse novo fato. Depois é saber que ela terá uma vida normal e será capaz de estudar, trabalhar e realizar muitos sonhos. Falando sobre a parte médica existe no começo do tratamento (geralmente as meninas descobrem Turner na faixa dos 10 anos) uma carga maior de consultas, acompanhamentos e medicações
Curtido por bellsribeiro_ e outras 24 pessoas
6 DE SETEMBRO
Adicione um comentário...
Publicar


Síndrome de Turner e a auto estima
Life is like riding a bicycle. to keep your balance, you must keep moving
Be yourself
turnereeu • Seguindo
turnereeu Hello pessoal
Hoje vim falar um pouco sobre auto estima.
Essa foto foi meu book de 15 anos e um dos dias mais legais da minha vida porque me senti linda. Meus pais não tinham condições de fazer uma festa, mas me deram o book de presente. E como a visão que temos quando olhamos no espelho afeta a forma como nos sentimentos.
Meninas ou mulheres com ST tendem a necessitar acompanhamento psicológico por causa da tendência a baixa auto estima. Quem tem ST sofre diversos preconceitos eu por exemplo era chamada na escola de "feia", "baixinha", "dentuça" e sabe foram essas pessoas que me fizeram
Curtido por biancalemossilva1901 e outras 46 pessoas
20 DE SETEMBRO
Adicione um comentário...
Publicar

- Focus on the personal experiences of the patient who is responsible for the page's content;
- Hybrid discourse: medical + personal;
- No pattern using the images (personal pictures or just text);
- The subtitles use and informal language, with slangs, oral marks and onomatopoeias;
- Some posts have and emotional character, showing an humanistic side;
- Although the interactions are not intense, the page's administrator answer every comment;
- Use of emojis and stickers on the subtitles and on the comments;
- Appropriation of Instagram – use it as a blog (personal details + long subtitles + focus on the text not on images);
- Page is from patient to patients and their families;
- It enables to show a different side of Turner Syndrome, presenting the uniqueness of the monosomy and making it real – outside doctor's books.

Final thoughts

- Turner Syndrome patients and their families use digital platforms as a source of information and as a space to look for support and understanding;
- The pages have the same target audience, but use different communicational strategies, which impacts on the meanings produce by the content;
- The communicational experiences allow the patients to see Turner Syndrome as something real and comprehend what are the implications of the monosomy;
- Both pages try to show a positive side of Turner Syndrome, which represents a distance from what is addressed by the media and the doctors' discourse;
- The page Turner & Eu gives a personal side of the syndrome, allowing the patients to identify their own stories with the life of the administrator;
- The page TSGA just make the information more visible, but do not put them in context.

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Thank You



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