

Digital Rights and young people with cancer: perspectives from Portugal and Brazil

Lidia Marôpo – Polytechnic Institute of Setubal; CICS.NOVA

Ana Jorge – CECC/Portuguese Catholic University, CICS.NOVA

Inês Vitorino Sampaio – Federal University of Ceará

Raiana de Carvalho – Federal University of Ceará



Media and
communications

Children's and Young People's Rights in the Digital Age

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Young people with cancer or survivors

How do children want to be represented in the (digital) media?

What opportunities and disadvantages they see in the disclosure of their images?

How do they manage their social networking sites in relation to cancer?

Do they search information about cancer in the digital media?

What kind of frameworks do they approve or disapprove?

How do they face their rights to privacy and participation in this context?

How do they use the media?

Cultural Studies

Childhood Studies

Children's Rights

Portugal

Characterization sheet

Focus group: 3 Participants: 12

Female: 4 Male: 8

Age: 13-22 Cities: Lisboa and Oporto

Under treatment or cured

Heterogeneous families



Brazil

• Characterization sheet; Participant observation

• Focus groups: 2 Participants: 8

• Female: 4 Male: 4

• Age: 12-20 City: Fortaleza

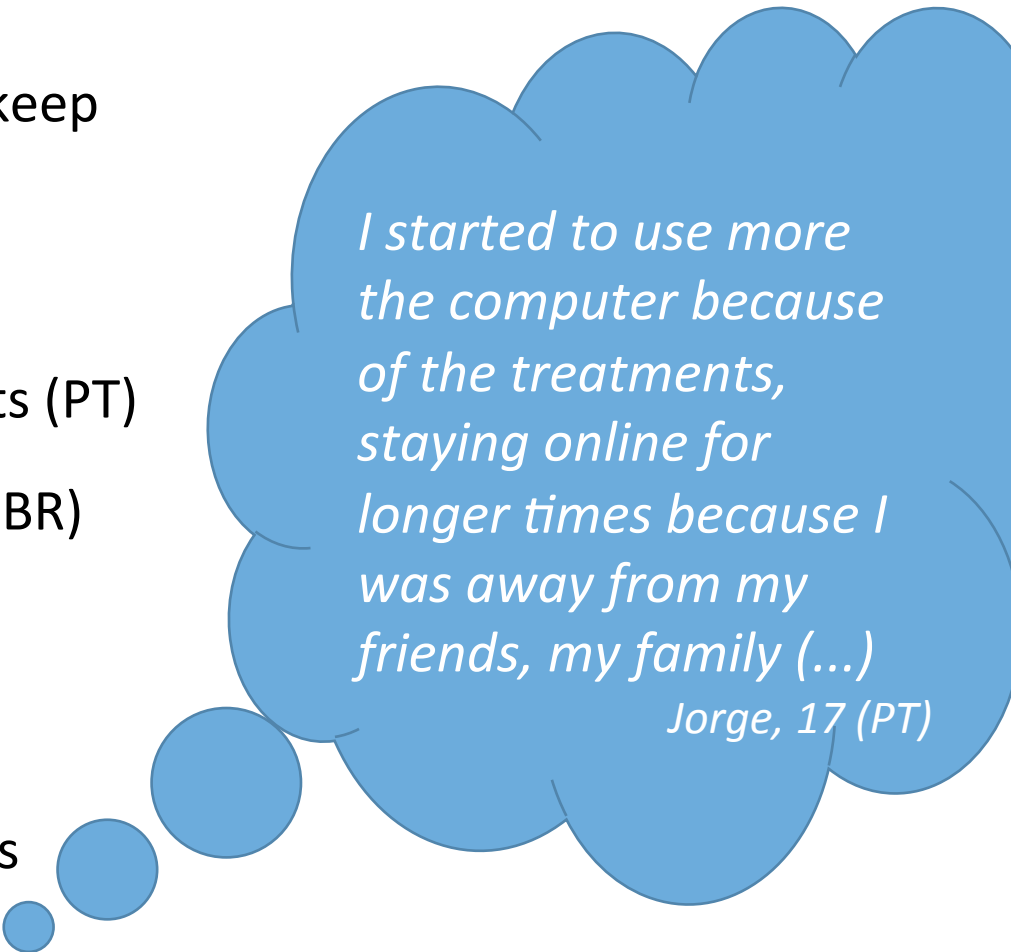
• Under treatment

• Parents with low-skilled jobs



Provision rights

- More intense use of media during treatment: to keep themselves busy and entertained.
- Critics to traditional media (TV):
 - schedule inadequate to their needs and interests (PT)
 - disclosure of children's image without consent (BR)
- Digital media:
 - interesting content available anytime
 - to maintain personal contacts during treatments
 - to keep in touch with friends met in hospital
 - source of health information.



I started to use more the computer because of the treatments, staying online for longer times because I was away from my friends, my family (...)

Jorge, 17 (PT)

Protection Rights

Privacy during treatment: doubts, pain, suffering and sorrows are 'personal'.

Reluctant to disclose images and information about the disease on Facebook.

Personalization of informed consent: negotiation of conditions and forms of exposure.

Disclosure of image and identity according to singularities.



Protection Rights (Portugal)

Using children in campaigns:

Discomfort of imagining themselves in a similar situation.

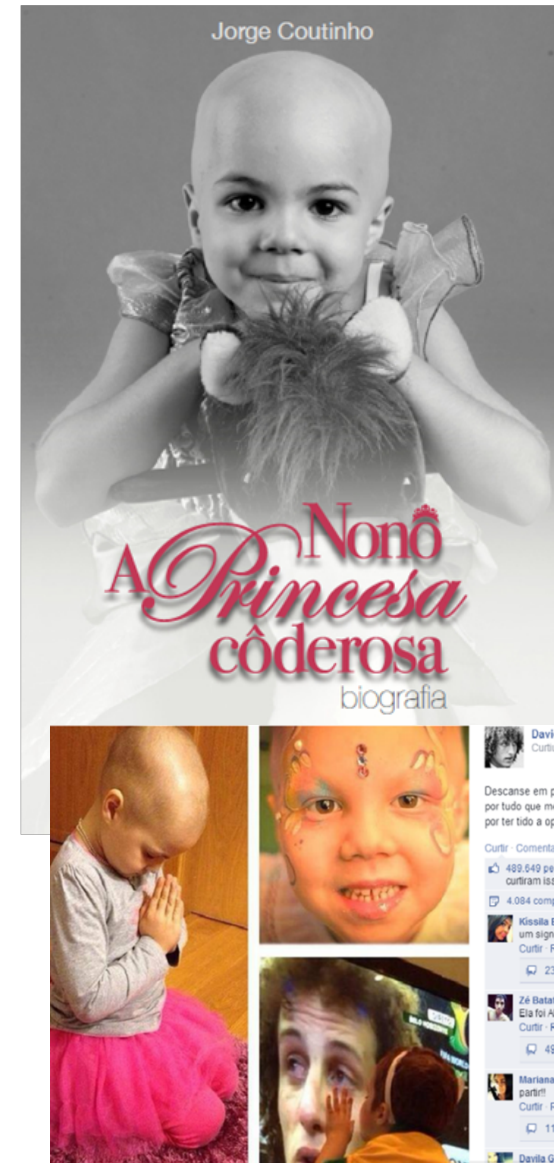
Suspicious about the real intention of the families.

What about the invisibility of many other sick children?

Lack of a more enlightening and contextualized debate.

Acceptance for the sake of potential benefits: bone marrow donors or financial aid for treatment abroad.

It could be a trump card for future action for the cause.



Protection Rights (Brazil)

Images sometimes captured
and used without consent

Parents complain it happens in the
institution.

Parents show more emotional
involvement with the institution
and are quite available to use
their own image to promote
more positive frameworks on
cancer and to help in campaigns
to raise funds.

I think that someone who's taking a picture should come and ask first... Some people get intimidated, they don't like it. And that's weird... You're there, a little embarrassed, someone taking a picture...

(Max, 20).

I think it's cool to show how well we're being taken care of here, that it's not just shots and chemotherapy, oh no. That it is also about affection and union.

(Patrícia, 16).



Participation Rights

- Young voices as a key contribution to the public debate about the disease: to give spontaneity and joy, to motivate peers, explain what is living with the disease, and give more 'realism'.
- Always available in anonymity.
- Disclosure of image and identity as an individual choice when overcoming the disease: positive framings.
- Recognition of those who spontaneously display their image: symbol of courage, self-affirmation and fight against stigma.



Conclusions

- **Privacy:** strategy to avoid dramatization, victimization and heroification during treatment.
- **Participation:** important to motivate, demystify and to fundraise (after treatment, including the disclosure of image and identity).
- Great emotional involvement with the institution and willingness to help in public campaigns:
 - ✓ Fundraising (Brazil)
 - ✓ Fighting the stereotype (Portugal)



Thank you!

diamaropo@gmail.com

