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Children's cancer narratives on YouTube: Agency and entrepreneurship in Brazilian CarecaTV

Abstract

This article looks at the social and cultural contexts of children's experiences of illness, through a particular focus on the context of the Global South and the role of the social media platform YouTube in children's culture. It takes a socio-constructivist approach to discuss the case of *CarecaTV* (BaldTV), a Brazilian YouTube channel with more than one million followers created by Lorena Reginato at the age of 12 when she was recovering from brain cancer. In *CarecaTV*, cancer subjectivity co-exists with and is expressed through digital commercialization. On the one hand, through this process, Lorena Reginato gains agency as she offers an inspirational and credible first-person testimony about cancer during childhood and becomes an emerging cancer activist. On the other, she uses entrepreneurship strategies associated with the digital influencer model of YouTube to promote herself as a (cancer) micro-celebrity, taking the lead in a youthful and playful culture.

Keywords: health; social media; YouTuber; influencer.

Introduction

Cancer is one of the most common causes of disease-related mortality in children worldwide. In Brazil, cancer is the leading cause of death from disease in children of ages 1 to 19 (Instituto Nacional de Cancer, 2020). Between 1996 and 2017, approximately one in two children of ages 0 to 4 died after a cancer diagnosis in the country due to factors such as the lack of a more accessible healthcare system, effective early diagnosis, and timely treatment options (Spironello et al., 2020). The context of underfunding with continuous budget cuts of the Brazilian Unified Health System results in insufficient resources for pediatric oncology (Pires, 2018) and helps to perpetuate the historical inequities in access to medical care for children with cancer (Grabois et al., 2011). Such health barriers serve not only to reduce overall survival time among diagnosed children (Selistre et al., 2016) but also interfere in how survivors experience chronic health conditions later in life (Cancer Atlas, 2019). Childhood cancer can

include experiences such as intense stress after diagnosis, painful and long-lasting treatments, short- and long-term physical and psychosocial effects, loss of a feeling of invulnerability, and the need to rebuild expectations about an individual biography (Jones et al., 2011; Song et al., 2012).

One of the Brazilian children who has lived through these experiences is Lorena Reginato, who created *CarecaTV* (BaldTV), a YouTube channel now with more than one million followers, at age 12, while recovering from brain cancer. This paper analyzes Lorena's digital narratives as a significant case of children's agency during pediatric cancer in Brazil. It explores the online opportunities and risks for young digital content creators with cancer in the Global South by discussing Lorena's performances on YouTube in Brazil's current reality.

To do so, the study adopts a socio-constructivist approach borrowed from the sociology of health and illness, of risk, and of childhood, as well as from media and cultural studies. It takes into consideration the social and cultural dimensions of children's illness in relation to the role of social media in today's children's culture. As such, the paper considers the 'child as health actor' (Brady et al., 2015), looking into children's lived experiences of illness and wellbeing to discuss their participation in the wider social and cultural understanding of children's illness, as well as in the particular configuration of YouTube at the time an influencer model is central to its functioning.

Illness, risk and narratives

To conceptualize the experience of illness, we draw on social sciences as well as culture studies to understand how different dimensions of social identity influence not only how individuals experience risk, in particular health risks (AUTHORS, forthcoming), but also how they deal with illness. In the social sciences, we can draw on the sociology of risk, of health and of childhood to situate children's experiences of illness. The sociology of risk has demonstrated that lay knowledge of risks is "highly contextual, localized and individualized and reflexively aware of diversity and change" (Lupton and Tulloch, 2002: 319). The perception of risks varies national and regionally, as well as individually, strongly depending on "such factors as gender, age, occupation and sexual identity" (ibidem: 332) and also via the "relation to their own life course" (ibidem: 331).

Sociology of health allows us to understand not only differences between classes in

experiencing illness in one particular country, but also differences between nations, as this field of study considers the social determinants of health, from micro-level (individual life factors) through meso-level (social and community networks) to macro-level (general socioeconomic, cultural, and environment conditions) (Raphael, 2019). Crucially, the child poverty rate is an “important social determinant of both child and eventual adult health” (*ibidem*: 148).

Lastly, the sociology of childhood has recognized the agency of children, as they are affected by but also affect the social world in which they live. In the field of health and illness, empirical studies involving children or from a child’s perspective are still lacking. Brady et al. (2015: 174) argue that conceptualizing children as a social group that establishes a relation to other social groups means that “different social settings, such as (...) healthcare settings and at school, but also prevailing discourses and images of the child in social and health policy” need to be considered. Furthermore, children’s agency does not equate with merely positive aspects, but should be contextualized as “bounded by and in intergenerational relations as well as in wider socioeconomic contexts and bodily, social and material resources” (*ibidem*). Lastly, children need to be understood as a diverse group in “ages, gender, ethnicity, socioeconomic circumstances and capacity” but also in national and regional contexts where they exercise choices in dealing with illness and participate in creating norms regarding their health.

A concurrent line of inquiry is that of culture studies, which explores how cancer has historically been embedded in metaphors that construe the illness as an enemy that abnormally invades and grows in the body (Sontag, 1978). In Western societies, it has often been perceived as a debilitating condition that leads to eventual death—a view that, by positioning patients as helpless and passive victims, can stigmatize and negatively impact their social interaction and self-perception (Fife and Wright, 2000). This view has been changing in recent decades: patients are now increasingly perceived as autonomous, self-enterprising subjects, responsible for making healthier choices and engaging in self-improvement to avoid risk, overcome illness and achieve health (Bell, 2012).

In the context of a global cancer culture, this has often been translated into narratives of restitution and heroic survivorship (Williams and Solbrække, 2018). Restitution narratives reproduce cultural expectations that conceive the healthy body as the normal condition people ought to restore (Frank, 1995). Along with the restitution narrative, the “cancer survivor” narrative has become hegemonic. It projects cancer as a trauma that should lead the patient to self-development and self-improvement, shifting discourses centered on death to discourses

focused on survival (Bell, 2012). While this narrative could be empowering for some patients, it can produce normative standards for how people should cope with cancer—i.e. patients should be positive and seek self-improvement—while silencing alternative responses—i.e. expressing sadness or anger (Bell, 2012).

For children and adolescents with cancer, responding to and making sense of illness are processes impacted by their age, stage of treatment, gender, class, and culture. During cancer recovery, children face a paradoxical identity struggle: even though they are no longer sick, they cannot go back to their lives before diagnosis (Cantrell and Conte, 2009), which can be especially challenging for “a group developmentally focused on identity formation” (Jones et al., 2011: 5). During early stages of treatment, children and adolescents who have not yet transitioned to a recovery state can also experience intense fears related to changes in the body, such as fears of losing hair, gaining or losing weight, looking different, or having part of their body removed (Carlsson, Kihlgren and Sorlie, 2008). Female adolescent oncology patients are at a high risk for negative body image, which can have psychological and social implications for that group such as feelings of insecurity (e.g. when their bodies do not conform to the perceived norm) and tendency to avoid social situations (Burg, 2016). Baldness, for example, was reported by adolescent girls in the study from Carlsson and colleagues (2008) as having implications for gender identity (e.g. when they were mistaken for a boy) and resulting in feelings of alienation, such as experiencing baldness as something unusual to their bodies (Carlsson et al., 2008). As previously mentioned, class also impacts their cancer experiences due to inequalities in access to healthcare, especially in countries such as Brazil, in which the public healthcare system suffers from insufficient resources (Pires, 2018). Finally, children’s experiences of cancer are always culturally situated. Culture provides them with the narratives and discourses that can shape their understanding of cancer and how best to cope with it. As Rindstedt (2016) argues, children with cancer produce their own stories in interaction with different social actors, negotiating different narrative positions while they navigate cancer treatment.

Online entrepreneurship and illness

Social media has been used for the sharing of illness stories, facilitating information sharing and co-creation of health knowledge among patients (Koteyko and Hunt, 2015). In the analysis of Knudsen and Stage (2015), these platforms facilitate the mediatization of illness, with

potential to generate affective responses from the audience and mobilize them to act. More specifically on the mediatization of cancer on social media, Stage (2017) observes that illness stories have been increasingly intertwined with entrepreneurship practices to enable the realization of personal, social, and political projects.

Among younger patients, scholars have explored how social media can enable teens to overcome health limitations (e.g. physical presence); maintain meaningful interactions with peers, or find and meet distant peer patients (Liu et al., 2015); share knowledge about emotional and social aspects of the illness (Gibson et al., 2016); and build feelings of empowerment and self-esteem out of chaos (Nesby and Salamonsen, 2016). These studies also emphasize opportunities for seeking normalcy and embracing a “new normal” identity through social media practices during illness (Gibson et al., 2016; Liu et al., 2015). Still, the extent to which social media can impact the patient’s experience of illness varies according to different factors, such as their age, ability to use platforms, and features of the technology (Patel et al., 2015). Likewise, these variations play a role in the ways chronically ill children narrate their experiences on social media.

The influencer model promoted by social media platforms, YouTube included, has also transformed youth digital narratives, including about illness (AUTHORS, forthcoming). Based on algorithmic architectures, the monetization of content, professionalization of ordinary producers and popularity as a central element (Van Dijck and Poell, 2013; Arthurs et al., 2018), this model rewards content producers economically for becoming professional creators (Bakioğlu, 2018; Raun, 2018). Micro-celebrity communicative practices are used as self-presentation techniques, in which social media users perform a public persona by strategically using intimacy and authenticity to increase visibility and engagement among followers, who are regarded as fans (Senft, 2013; Marwick, 2015). Popularity is one of the driving elements of social media logics (Van Dijck & Poell, 2013) and can be a path to one of the ultimate goals of many ordinary young internet users: to become a digital influencer (Jorge and Nunes, 2019). Broadly used, the term refers to content producers “who accumulate a relatively large following through the textual and visual narration of their personal lives and lifestyles” while at the same time “monetizing their following by integrating ‘advertorials’” (Abidin, 2016). The young creators on YouTube turn into a ‘community of practice’ (Lange, 2014) in which playing is transported from the private to the public sphere, thus putting content producers in a position of social relevance. Alongside ‘playful capital’ (Tomaz, 2019), they also act as ‘new taste agents’ (Hutchinson, 2017) showing what they like to do and their cultural tastes (e.g. personal

preferences for music or TV shows) while promoting the ‘proto-industry of social media entertainment’ (Cunningham and Craig, 2017).

In this context, social media represents an opportunity to narrate cancer experience and engage in entrepreneurship, as previously mentioned. Nevertheless, digital cancer narratives involve dealing publicly with the challenge to define how one is seen by oneself and how one wants to be seen by others (Ting-Toomey, 2016). This process also involves the challenge of achieving public recognition (e.g. measured by the numbers of subscribers, views, comments, and likes).

Among (popular) girl YouTubers, the management of intimacy is essential to construct a trustful emotional connection with followers (Marôpo et al., 2020). This intimacy is achieved by emphasizing an ordinary, everyday persona, sharing personal information, and making an effort to look familiar and close to fans. The online personae of popular girls have been found to be particularly influenced by popular feminism in an individualistic logic of self-entrepreneurship and normative femininity that supports platforms’ instrumental economic imperatives (Senft, 2013; Hearn and Banet-Weiser, 2020). Thus, in what concerns how much they disclose about their illness experience, cancer narratives involve greater consideration for maintaining privacy while at the same time managing online reputation (Hausmann et al., 2017)—the so-called ‘privacy paradox’ (van der Velden and El Emam, 2013).

Methods

This paper analyzes the case of *CarecaTV*, a YouTube channel launched in March 2016 by Lorena Reginato, a Brazilian girl then aged 12 who was recovering from brain surgery. The channel had 1.7 million subscribers as of March 2020. Lorena had posterior fossa tumor, a brain cancer that can affect balance, motor coordination and vital body functions (MedlinePlus Medical Encyclopedia, n.d.). After surgery Lorena’s motor and speech skills were impaired. She requires a wheelchair to move around and speaks slowly and in higher-pitched tones.

When she created the channel, Lorena was living in Jaú, a municipality of the state of São Paulo, with an estimated population of 150,000 in an area of 687,103 km² (IBGE, 2019). The closest municipality with available treatment is Ribeirão Preto, 150 km away. In addition to chemotherapy sessions and hospital follow-ups, Lorena also needed physiotherapy and speech therapy.

In Brazil, many low-income families still face barriers to access healthcare for their children. Brazil’s Unified Health System (SUS) still struggles with underfunding and infrastructure and

human resources constraints, resulting in limited availability of health centres, doctors, and drugs, as well as long waiting times (Garcia-Subirats et al., 2014).

This study takes this social context into account when analyzing the content of the videos shared by Lorena on YouTube as well as the content from other media productions about her trajectory as a YouTuber. As such, the analysis consisted of a qualitative coding of the videos posted on *Careca TV* (based on partial transcription, explained below), complemented by an exploratory analysis of paratextual materials about Lorena and her channel (e.g. news, website articles etc.). We analyzed all videos shared between March 26, 2016 (when the first video was launched and Lorena was in treatment) and March 29, 2018 (two years later, when she was in remission), comprising a corpus of 90 videos. In parallel, the exploratory analysis of paratextual texts consisted of mapping Lorena's media presence by using Google alerts and accessing the media content that Lorena referenced in her vlogs.

In the first step of the data collection, between March and May 2018, we watched all the videos and systematized data about each of them in descriptive tables, including: title of video, date of publication, duration, number of views, number of likes and dislikes, number of comments, general nature of comments (e.g. support or criticism), and rich qualitative descriptions of their content. We transcribed the content that was considered most relevant to the scope of the research.

This material was then submitted to a thematic analysis through inductive coding. The coding process started with primary-cycle coding (Tracy, 2013), initially conducted by the second author, who began assigning tentative descriptive words and sentences that captured the main topics discussed and actions performed in Lorena's videos. For example, some topics were coded as 'side effects and disability', 'physical pain or discomforts', 'personal preferences', 'student's life'. Some of the actions performed were coded, for example, as 'clarifying cancer experiences', 'interacting with fans', 'responding to fake news, criticism, and bullying', 'involvement with brands'. The codes were organized into a codebook displaying their respective definitions and representative examples, which was shared through Google Doc with the two other authors. From then, the co-authors worked together "to try to become consistent in their understanding" of the data (Tracy, 2013: 237) by checking the tentative codes with the content of the previous descriptive tables. For the process of secondary-cycle coding (Tracy, 2013), the co-authors critically discussed the codes together and began to group them into interpretive categories. Two main overarching themes were identified by the authors and

solidified by literature: cancer and micro-celebrity performances. The study relies only on publicly available material and we chose not to include Lorena's visual image in the analysis.

Results

Cancer performance

Lorena's performance as a cancer patient is essential to her digital practices on YouTube. One of the main ways in which cancer appears in Lorena's digital performance is through her baldness. This side-effect of cancer treatment not only gives the channel its name but also becomes a topic of discussion in several videos, in which she often expresses pride at being bald, as she did in her introductory video: 'I am bald—look at this pretty bald head—because I had cancer' (Reginato, 2016). Lorena rarely hides her baldness and is called 'the Bald one' by different people in her videos. Similarly, she greets her viewers as if they are members of a group of bald people by calling them 'carecas' and 'carecudos'—a Portuguese word for bald people and a derivative. Even when her hair starts to grow back, Lorena maintains baldness as a defining element of her persona. She replaces the word 'carecudos' by 'cabeludos'—'hairy people'—but maintains the word 'careca' (bald) to refer to cancer patients.

Lorena's emphasis on baldness may challenge gender expectations that girls and women should have long hair. While her channel incorporates the pride of being bald as a central element of her digital performance, she is also reminded through potentially offensive comments that baldness does not conform to current gender norms. She addresses the issue of being mocked online due to these gender expectations, for example, on March 29, 2018: "People would say 'what shampoo do you use? What hairbrush do you use?'... So, I can say that I suffered a lot of bullying not only for not having hair but also because people had no idea what I'd been through" (Reginato, 2018). Comments such as those could be felt by Lorena as a threat to her conception of self (Carlsson et al., 2008) and interfere in her coping process.

Lorena's representation in Brazilian media also focused on the growth of her hair as one of the main aspects of her recovery, which could be read as a similar gender expectation regarding her coping process. In a newscast broadcast on July 17, 2017 by a local television affiliate—content that Lorena reposted on her channel—both anchor and reporter associate her recovery with hair regrowth and beauty standards: 'Lorena, from *CarecaTV*, has it all now. With her hair grown and taking great care with her appearance, she is going to launch new content on

the internet' (Reginato, 2017). The reporter also records Lorena and her mother in a beauty salon, stating that to better interact with fans both are 'all made up' (Reginato, 2017). Such representations rely on ideals of femininity that emphasize hair and appearance as primordial concerns for girls.

Lorena also incorporates cancer in videos that invite viewers' empathy and sensitivity, sometimes to mobilize them to help her financially. By mediating her illness and vulnerability, Lorena activates affective responses from the audience (Knudsen and Stage, 2015), who feel compelled to act in her favor. On July 20, 2016, she explained how the trip to and long waiting times at health centres could be a source of suffering: 'I hate to wake up at 5 in the morning, to go in a horrible van—though I am grateful for that because it takes me there—then I go back home with back pain... Then you get there at 7 AM; then you keep waiting to have your blood taken...' (Reginato, 2016). A year later, Lorena tries to mobilize supportive viewers to help her financially. She uses *CarecaTV* to promote her fundraising to buy a car, so that she can travel more easily to treatments, even though she is careful about the degree to which she presents herself as a victim: 'this is a true campaign, but I'm not begging for anything ... I understand that there are a lot of people like me who don't get help. But I ask, please, for you to help. Because I really need it. It's very difficult for me to have to go to speech therapy, to the physio[therapist], anywhere' (Reginato, 2017). She was able to raise around R\$40,000 (US\$8,230—currency rate as of March 2020).

While identifying as a cancer patient resulted in financial gains, this also made her a target of stereotypical constructions about cancer. Her haters reinforced the narrative of cancer as a death sentence when they spread false news that she was dead. Lorena denies this on June 22, 2016, when she also tries to deconstruct that narrative and affirm that she will live longer: 'They manipulated an image of me as if I had died, but I'm very much alive. And I'll stay alive for a long time, with God's willing' (Reginato, 2016).

At the other end of the spectrum, Lorena and supporters rely on a restitution narrative (Frank, 1995) when discussing cancer, in which they express the expectation that she will recover the state of health, and the body, she had before cancer. This is observed on June 26, 2016, when a follower asks whether she will speak 'normally' again, to which she replies: 'Yes, I will, I'm attending speech therapy sections and, in some months or years from now, my voice will be normal again' (Reginato, 2016). Lorena also reproduces the survivorship narrative (Bell, 2012) when projecting herself as a survivor who made the choice of fighting for her life to overcome

cancer. On May 9, 2016, for example, she explains how she coped with the diagnosis: “The first thing I did was to cry a lot. But then I said: ‘I can die without trying to live, or I can die trying.’ Then I said: ‘I’ve got nothing to lose, so I’m going to try’” (Reginato, 2016).

Entrepreneurial micro-celebrity performance

In her inaugural video on *CarecaTV*, Lorena directly mentions her dream to create a ‘successful YouTube channel’. This also implies deploying micro-celebrity techniques to become a ‘YouTuber’, a widespread aspiration among digital creators who want to enjoy the social and financial gains from this status. In order to pursue this goal, she invested in several complementary strategies that can also be identified among popular teen YouTubers.

Lorena reproduces the common culture of YouTube (Burgess and Green, 2018) in which entertainment and playfulness play a pivotal role. Sitting in a gaming chair, she frequently records online sessions of popular games such as Minecraft. Some of these videos are tagged as ‘Careca’s Adventure’ series, in which she plays Minecraft with two other YouTubers; others are tagged as ‘World of Lorena series’, in which she plays the same game alone. Alongside with other popular youth fun formats, like ‘challenges’, ‘mock videos’, ‘unboxing’ and ‘vlogs’, Lorena promotes a form of ‘playful capital’ (Tomaz, 2019), mirroring other popular female Brazilian YouTubers in the transition from childhood to adolescence. This can be associated with positioning herself as a ‘new taste agent’ (Hutchinson, 2017). On October 18, 2016, for example, she identified five songs from her personal playlist. She plays excerpts of the songs and sings and dances in front of the camera.

These playful formats recurrently intersect with her cancer experience. Sometimes she apologizes for longer periods of video absence, justifying it with school obligations, but mainly with the intensity of treatments. Frequently, during games, she feels the need to explain her appearance and physical limitations (baldness, shaky voice, impaired motor skills) as side effects of her cancer treatment and to adapt her performance to her condition. When she displayed a Brazilian funk playlist—a genre originally from the slums—she justified herself: ‘Guys, as I can’t dance really yet... So, I stop the songs before they finish ... The intention was to show the songs I’m listening to the most at the moment’ (June 16, 2018).

Like other female teen YouTubers (Marôpo et al., 2020), Lorena seeks to build a connection with her followers by sharing these tastes and aspirations, as well as personal information about family and school life. The difference here is that cancer experiences are central to her

narratives. Cancer treatments (such as chemotherapy and occupational therapies), difficulties relating to treatment (such as seeing peer-friends dying, waiting longer hours for treatment, physical discomfort etc.), descriptions of side effects (baldness, motor limitations etc.) and stories of recovery all serve to create an emotional connection.

Cancer is also at the core of her brand strategies, from the name of the channel to the official logo (a caricature of a bald Lorena wearing a hat) and how she addresses the audience. Moreover, her book '*O Sonho de Lorena. Uma História de Superação e Coragem*' (*Lorena's Dream: A Story of Resilience and Courage*) also refers to her fight against cancer and has on the cover a photo of her when she had gone bald due to chemotherapy. Her framing in traditional media is also connected with cancer identity in stories that mimic her book's central idea of courage and overcoming adversity.

Lorena juxtaposes cancer identity and self-promotion, legitimizing her raising of funds for her personal treatment and endorsing cancer-related awareness campaigns, fundraising campaigns and non-profit organizations supporting cancer patients' recovery and treatment. In addition, she starts receiving 'gifts' from children's brands that she shows in her videos (a common marketing strategy used with popular young YouTubers), which is a way of capitalizing on her visibility as well as a symbolic and legitimizing recognition of her status as a micro-celebrity.

The entertainment performance in *CarecaTV* also surfaces when Lorena narrates her cancer experience while playing with other peer-patients, usually in activities promoted by non-profit organizations. One example is her first daily vlog, from November 14, 2016, recorded by her sister Lara, of themselves and their mother at a resort with other child cancer patients and families (Reginato, 2016). The intersection of different entertainment formats and themes with her cancer experiences shows the specificities of her health condition and her involvement with the digital influencer model of YouTube. When Lorena records gaming sessions or other fun activities with other YouTubers, for example, this could also be seen as a strategy to increase the popularity of both content producers. On June 1, 2016 she launched the challenge of reaching two million followers and having Leo's *Populose* channel reach 100,000 followers. In that case, they would do a joint challenge to be chosen by viewers.

She constantly asks for audience engagement, either to increase her number of followers or for viewers to contribute content and suggestions for her videos. She does live videos and responds to questions in her series '*Careca Responde*' (Baldie Answers). On March 26, 2018 she said that she would release videos every day that week and if the videos received many likes, views,

and good comments, she would upload more videos. The ‘challenge’ formats also arise from viewer requests or from taking up challenges that became viral on the internet at that time, which shows how she tries to navigate algorithmic functioning and be a part of YouTube culture (Jorge and Nunes, 2019).

Discussion

Lorena’s cancer experience is central to the narrativization of her personal life on the *CarecaTV* YouTube channel. The illness is at the core of her intimacy capital, enabling connection with followers, status, and social recognition as a cancer survivor. Likewise, cancer permeates the branding of the channel through different strategies, such as by incorporating baldness into her online identity, captivating supporters by including them in the group of bald people and identifying with cancer-related charities and campaigns. At the same time, she draws on and contributes to Brazilian cultural understandings of cancer through interactions with different segments of her audience—from supporters to haters and the media—who often judged her based on her status as a cancer patient. As she participates in YouTubers’ community of practice and applies self-branding strategies, Lorena both confirms and counters those social and cultural constructions.

The ways that Lorena incorporates cancer narratives into an online entrepreneurial presentation seem effective not only for emotional catharsis and audience understanding but also for transforming these into financial support and advocacy projects. Indeed, Lorena’s success on YouTube has been recognized by other social actors in Brazil as a source of mobilization for cancer-related social action. This potentially increases her visibility and credibility as a prominent public figure among the social group of cancer patients, from a young person’s perspective. Moreover, it strengthens her dialogues with civil society actors in a country where social movements have historically been a driver for social change—including in healthcare.

While this social recognition in Brazil represents opportunities for Lorena’s civic engagement and participation in public life, this visibility also was also the object of judgements infused with stereotypical constructions about cancer. Problematic misconceptions about cancer diagnosis, such as that cancer equals death, were used to attack and bully her online. She also had to negotiate normative feminine ideals of beauty and hair growth during cancer recovery, which she both resists and reproduces at different moments of *CarecaTV*.

Lorena also negotiates different narrative positions about survivorship and restitution when

interacting with followers. Often, these narratives are appropriated by Lorena in empowering ways when she emphasizes her self-determination in recovering her health through stories of survivorship. At the same time, the reliance on a restitution narrative could represent an additional source of conflict for Lorena. The notion of complete recovery that this narrative invokes tends to establish the healthy and able body as the normal condition to be restored, while implicitly constructing her disability as a transitory, abnormal state that she must overcome. Since cancer, as a chronic condition, can return even years after treatment is done, and childhood cancer can leave long-term side effects, such ideals could add an extra burden to Lorena's process of coping and adaptation to her life after cancer.

Conclusions

The intersection of a commodification process with digital cancer self-narratives in the context of childhood lived in the Global South makes *CarecaTV* a distinct case. Here, cancer subjectivity co-exists with and is expressed through digital commercialization. On the one hand, Lorena Reginato became a self-enterprising subject in overcoming the disease as she offers an inspirational and credible first-person testimony about cancer during childhood turning to an emerging cancer activist. On the other, she uses entrepreneurship strategies connected to YouTube's digital influencer model to promote herself as a (cancer) micro-celebrity, taking the lead in a youthful and playful culture. These strategies include self-branding, monetization, partnership with brands, playfulness as a form of capital, confessional formats permeated by claims of authenticity and intimacy, constant interconnection with followers, and a search for cultural legitimacy in the digital sphere and beyond—through the book and visibility in traditional media. All of these are permeated by cancer narratives.

CarecaTV is also a case of the contextual and situated nature of risk as well as health experiences, namely by the weight of cultural and individual (gender, age, disability) determinants. Mediating her vulnerability through YouTube videos helped Lorena Reginato monetize her visibility to seek quality of life during treatment. She was therefore able to counter the disadvantageous condition of the disease and the deficient healthcare available to her, turning these into an opportunity to gain agency. In the process, she faces new risks that result from interacting in a public sphere, against social expectations of how a sick young girl should behave, as someone whose intimacy and vulnerability has been revealed. Furthermore, the model of success for online entrepreneurship is built on exceptionality, and thus opportunities

are unequally distributed, as well as mediated by the social media platform.

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