The Routledge Companion to Digital Media and Children

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Publication details
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Published online on: 28 Oct 2020

How to cite: Ana Jorge, Lidia Marôpo, Raiana de Carvalho. 28 Oct 2020, Sick Children and Social Media from: The Routledge Companion to Digital Media and Children Routledge
Accessed on: 21 Nov 2023

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SICK CHILDREN AND SOCIAL MEDIA

Ana Jorge, Lidia Marôpo, and Raiana de Carvalho

Introduction

Social media, as a particular form of digital media, occupies a significant role in the everyday life of children and young people across the world for various personal and public purposes (boyd, 2010, 2014; Mascheroni & Ólafsson, 2014). Although research on digital media use by children and youth has long focussed on risks and negative outcomes (Livingstone, Mascheroni, & Staksrud, 2015), recent studies have identified some positive health impacts of digital media upon children’s physical, psychological, mental (Goodyear, Armour, & Wood, 2019, p. 674), and emotional well-being, improving their social skills online, developing character, and offering support (Frith, 2017), and also in providing leisure activities, relieving stress, fostering creativity, and facilitating learning (Swist, Collin, McCormack, & Third, 2015). Although social media can be a productive place for health education, delivered by professional health providers and also children’s peers, it can also lead to inaccurate information and the normalisation of bad health choices, e.g., regarding food (Holmberg, Chaplin, Hillman, & Berg, 2016). Moreover, young people might wish to avoid being associated with certain health information if it compromises their privacy and the desired self-presentation (Byron, Albury, & Evers, 2013).

This chapter examines social media and children in the context of sickness, offering a literature review that is predominantly drawn from medical sciences, children/youth media, and digital media studies. It also considers the affordances and constraints of social media for children and young people, before discussing a case study of a teenager living with cancer and using YouTube to chart her journey. The chapter finishes by arguing for a perspective that considers intersectionality in combination with a framework of children’s (digital) rights, positioning children’s well-being within the interaction of online and offline realms.

Networked Illness

While there has been extensive research into children’s (aged 0–18), and especially young people’s (teenagers’) use of social media, few studies have considered the types of health-related information young people come into contact with, create, and share through social media (Goodyear et al., 2019, p. 674). Social media can offer health information both from institutions and from peers via user-generated content (Hausmann, Touloumitz, White, Colbert & Gooding, 2017). Such content is often circulated in a context of entertainment and sociability. As
a consequence, health information is increasingly accessible to young people, being “more available, shared and tailored” (Goodyear et al., 2019, p. 674). Indeed, health providers have acknowledged the many positive possibilities offered by digital media for communication with teenage patients with chronic illness (Santos, Tavares, Ferreira, & Pereira, 2015). Two obvious risks posed to younger patients are, however, the threat of encountering inaccuracies and unreliable sources online, and feeling overwhelmed by the amount of information on offer (Frith, 2017).

Young patients and their families may also experience social benefits, such as “increased interaction [and] peer/social/emotional support” (Goodyear et al., 2019, p. 674), empowerment through network building, acceptance, and belonging to society; understanding, and validation and information sharing amongst online community members (Merollı, Gray, & Martin-Sanchez, 2013; Pruulmann-Vengerfeldt, 2018; Stage, 2017). While providing a space to potentially help a child cope with illness, social media resources can also constitute ‘networked publics’ (boyd, 2010) around ‘health-related interests’ including chronic and rare diseases (Wittmeier et al., 2014). The notion of a ‘networked illness’ as supported by social media offers the possibility of co-creating and sharing new knowledge that is shaped by a child’s personal experience (Koteyko & Hunt, 2016), shifting the reliance from professionally delivered expert knowledge to positioning the patient as an expert, and in turn challenging the authority of medical practitioners.

For sick children who might need to travel away from their homes and/or schools during treatment, communication technologies and particularly social media play a pivotal role in maintaining a connection with their social circle. Young cancer survivors have reported that during treatment they increase their use of digital media for both entertainment and for contacting their personal networks (Jorge & Marôpo, 2017). These technologies also allow chronically ill children to participate in special or everyday activities at a distance (e.g., through video chat) and to receive updates and encouraging comments (Liu, Inkpen, & Pratt, 2015). Social media use enables children to receive information about their illness from (more experienced) peer patients, and to educate their healthy peers about their experience of the illness (Merollı et al., 2013).

Social media interaction helps constitute the social (e.g., cultural and ethnic membership) and personal identities (e.g., unique attributes) of sick children (Ting-Toomey, 2016). Digital media, especially social media, acquires special importance in the context of suffering or overcoming serious illness and forms part of the child’s identity work, helping to define how children view themselves and how they want to be seen by others. Even when young people share a lot of personal information online, however, they remain concerned about maintaining personal privacy and managing their online reputation (Hausmann et al., 2017). These priorities seem a common preoccupation for (teenage) users of social media, in what has been termed the ‘privacy paradox’ (Van der Velden & El Emam, 2013).

Few studies of teenage patients and social media focus on the topic of privacy. Teenagers with chronic or long-term illness seem to be selective about sharing feelings and thoughts about their diagnosis, treatment, and prognosis as a means of protecting themselves (Van der Velden, 2012), and “to prevent or reduce the likelihood of embarrassment, difficult questions, and feelings of vulnerability” (Van der Velden & El Emam, 2013, p. 19). Such emotional imperatives are not fixed, but evolve over the different stages of the illness. Instead, young people with chronic health conditions may choose to promote themselves as regular teenagers (Van der Velden & El Emam, 2013), and use social media to manage real-time reactions, e.g., by sharing progress pictures or their new appearance before going back to school (Merollı et al., 2013). Thus, social media use provides a degree of choice and control for children and young people over how they might present and assert themselves, as well as regarding how much they disclose about their condition. Even so, young patients’ decisions to restrict privacy settings are sometimes made difficult by the user-interface design of social media platforms and apps, which may lead to an illusion of control (Van der Velden, 2012).
Social media also provides an opportunity for children with chronic and serious diseases to narrate their experiences (Gibson et al., 2016; Merolli et al., 2013). Some sick children and young people share their stories, reflections and questions through digital channels such as blogs, YouTube, Instagram, and Facebook. They may be looking for emotional catharsis, audience understanding, sympathy, and support in coping with their disease and, at times, hoping for advocacy (Nesby & Salamonsen, 2016). Potential positive benefits are the prevention of feelings of isolation, softening the mental stress of being seriously ill, promotion of an interactive social life, public self-expression, participation in the construction of young people’s community, and the experience of a novel form of social agency in which it is possible to create meaning from distress (Nesby & Salamonsen, 2016). The use of social media to discuss and reflect upon their illness may also provide an opportunity for entrepreneurship (Stage, 2017). Sick children who are active on social media can act as role models by spreading knowledge about how to live proactively with a serious disease, offering exceptional examples of courage and self-assertion while discussing the struggle against stigma. Nevertheless, from a critical perspective, children’s use of social media to disclose a personal experience of illness may run the risk of falling into exhibitionism (Nesby & Salamonsen, 2016).

Although there are a range of potential benefits, not all social media interactions are supportive. Some comments may be intrusive, suspicious, critical, or insensitive (Merolli et al., 2013, p. 8), and these responses might be stressful for young people. Given this, some children might prefer comparatively anonymous online spaces where they can discuss sensitive topics at ease (Nesby & Salamonsen, 2016). In addition, some studies of young cancer survivors demonstrate that they avoid dramatisation, victimisation, or heroification by actively protecting their privacy, rather keeping their emotional labour around their illness to the personal sphere of their family and close friends (Carvalho, Sampaio, & Marôpo, 2016).

Sick children can also be represented on social media by others, such as relatives, peers, or advocacy groups. Even if social media provides more agentic opportunities for teenagers, young children can be involved as well, for instance through parent-initiated and parent-led social media campaigns (Jorge & Marôpo, 2017; Wittmeier et al., 2014). Some young cancer survivors express discomfort at the possibility of picturing themselves in this type of digital campaign while others accept it, hoping for the possibility of significant benefits such as bone marrow donors, or funds for treatment, or to build a persona for later activism (Jorge & Marôpo, 2017). Sometimes, peers may share pictures or other information about a sick child through social media. This can be problematic, for example, if a friend tries to give support by sharing a picture of them with the sick child without their consent (Carvalho et al., 2016).

Besides campaigns by sick children’s parents, many advocacy and awareness-raising campaigns use social media for a myriad of purposes. For example, to challenge negative stereotypes, to find bone marrow donors, to promote health literacy, to raise funds (individually or institutionally), to support research, and to improve therapeutic options available for a patient, and for others. One such Brazilian campaign was found to have disclosed significant information about individual sick children and to have promoted children as victims in ways that the children resented (Marôpo, Carvalho, & Sampaio, 2015), however. Informed consent and the active participation of children in such campaigns, in ways that consider and uphold children’s dignity, comfort, and safety, should be the minimum requirements for best practice in this area.

All these different activities use social media to help construct the social meanings of diseases affecting children while promoting aspects of their identities. Social media use offer benefits as well as a range of risks, while potentially emphasising existing inequalities. Yet, social media can also bring new challenges to children and their families at different stages of an illness, requiring both awareness and a range of competencies.

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A Case Study: Lorena Reginato and CarecaTV

“Globally, childhood and adolescent cancer is threatening to overtake infectious diseases as one of the highest causes of disease-related mortality in children” (Childhood Cancer International, 2018). While the incidence of child cancer is lower than that in adults, and despite the fact that children tend to respond better to cancer treatment than adults, children are more likely to have side-effects since their bodies are still growing. Moreover, if the treatment causes long-term side effects, this may require children to have careful follow-up for the rest of their lives (American Cancer Society, 2019). The concern with childhood cancer is increased in the case of low- to middle-income countries: not only do 80% of children with cancer live in low- to middle-income countries, but the survival rate in these countries can be as low as 10%, while in developed countries it can be more than 80% (Childhood Cancer International, 2018). In this section the authors analyse the case of YouTube channel CarecaTV (BaldTV, with 1.8 million subscribers as of January 2018), created in 2016 by Lorena Reginato, a Brazilian girl then aged 12, who was undergoing treatment for brain cancer (Reginato, n.d.; G1, 2016). Produced by a girl from the Global South, the case also demonstrates the situated nature of these experiences, with Brazil being the second largest user of YouTube in comparative country terms (Dogtiev, 2019). This case study therefore lends itself to a rich discussion about the possibilities and challenges of networked illness among children and youth. This section draws upon a conceptual framework that discusses the emergence of cancer identities and how they are intertwined with the patient’s online practices. Further, the case study exemplifies the application of a proposed framework for studying sick children and social media.

The most common post-cancer identities adopted by adults (Park, Zlateva, & Blank, 2009) are ‘survivor’ (encouraged by advocacy groups and health care professionals and correlated with greater mental well-being, post-traumatic growth, and involvement in advocacy) and the more neutral ‘person who has had cancer’ (correlated with cancer-related activities and a stronger sense of life purpose, but also with concerns about recurrence). Less frequently, individuals identify as a patient post-treatment, which is a more passive posture, indicating a decision to remain vigilant concerning recurrence, and as a ‘victim’, which shows passivity and continued vulnerability, related to reduced well-being but also, surprisingly, to a greater involvement in cancer-related activities.

In her inaugural video, Lorena presented herself as someone who had cancer. She had undergone brain surgery and experienced side-effects made evident in the video. She explained:

I’m bald – look how beautiful this bald head is … I have a high-pitched voice and talk a little slowly, but don’t you mind about this, OK? Sometimes I shake a little, but don’t mind, I am normal … I’m not walking yet, but I will walk again.

(26/03/2016)

Rather than focussing on a detailed account of her illness trajectory, Lorena emphasised she was ‘normal’ and wanted her channel to focus on game playing.

However, as CarecaTV gained online and traditional media recognition, Lorena’s narration of the different stages of her cancer treatment became more prominent and she began to respond to questions and comments from her audience. Adopting the identity of a patient, Lorena described the challenges and inherent suffering as part of her treatment, expressing her uncertainties and the struggle to find meaning in a life-crisis situation: “sometimes in the afternoon I cry with my mum, a lot. Really, I ask ‘why with me, what have I done?’ But, it’s like, crying won’t help, it only helps to express my anger” (29/03/2018).
Children’s and young people’s experiences of cancer are filled with challenges: intense stress post-diagnosis; the side-effects of the treatments; the need to rebuild their imagined life trajectory; and dealing with feelings of vulnerability (Jones, Parker-Raley, & Barczyk, 2011). As with other sick children, Lorena’s engagement with social media often worked as a form of distraction from these challenges: “when I’m very sad, what I do often times is going to Instagram, Snapchat, Facebook, Twitter, you know, then I check the messages” (29/03/2018). Crucially, her social media visibility has been a source of support and encouragement:

when I felt discouraged, I decided to make this channel to distract myself. That was when you all helped me, a lot, by sending me messages of support, by telling me to go on, giving me strength and, because of that, I’m happy.

(18/01/2017)

Videos about being a patient also help educate viewers about cancer treatments. Lorena recorded a chemotherapy session in the hospital with her cell phone, explaining the procedures and showing the environment in which it takes place (21/10/2016). She answered questions from followers on the effects of chemotherapy, as well as social side-effects like bullying (29/03/2018). In offering her experiences, Lorena positioned herself as a health-literate young person, symbolically bringing teenage sufferers of cancer into the public sphere and challenging the conception of illness as something private or socially invisible (Stage, 2017).

Nevertheless, Lorena had to deal with offensive and hateful comments, including false information being spread online about her having passed away, the hacking of her channel, and a mocking ‘I also have cancer’ video by another YouTuber. Some of her videos responded to criticism and invited sympathy. For example, she commented on the suffering and anxiety that young people who have had cancer go through, and condemned the insensitive remarks directed at them (20/07/2018). In this way, Lorena is negotiating a revised awareness of online ethics.

Not only does an individual’s background, psychological factors, and different aspects of the experience of the disease affect how cancer survivors form these identities (Park et al., 2009), but they also change over time (Cheung & Delfabbro, 2016). The experience of cancer during childhood, which is an essential time of identity formation, can significantly disrupt a person’s self-conceptualisation and identity-construction (Song et al., 2012), and, consequently, their social cognition, affective being, and behavioural tendencies (Ting-Toomey, 2016). In CarecaTV, Lorena combined her presentation as a patient with that of a survivor, embracing a process in which overcoming cancer is associated with a battle. She used fighting metaphors infused with optimism and hope. For example, Lorena recalled when she first learned she had cancer: “the first thing I did was to cry a lot. Then I said: ‘well, I can die and not try to live, and I can die trying’” (09/05/2016). She also talks about her cancer experience as a means to emphasise that she has completed her treatment. For example, when answering one of her followers about how she felt after she overcame cancer, she said: “I’m glad I won, I am strong, I will always be” (26/06/2016). Lorena also shared her plans for the future and focussed on her good health (Jones et al., 2011): “I hope that 2018, now, can be a year of victories because this year I have a lot of things to do”. Her positive activities included equine, occupational, and speech therapies, as well as physiotherapy and swimming. These plans are entwined with her normal life as teenager: “I’m going to start high school in a very cool school … I’m super excited to get to know new people, to study” (09/01/2018).

During recovery, children and young people go through several physical and cognitive changes, psychological experiences (such as poor performance at school, anxiety, depression, and fear of recurrence), and a range of social side-effects (including isolation, poor peer relations, and some limitations associated with their frail physical condition, such as not being allowed to play
sports) (Jones et al., 2011). As part of this process, children face a paradoxical identity struggle: they are not sick anymore, but they cannot go back to the life they lived pre-cancer diagnosis (Cantrell & Conte, 2009). Likewise, they must reinvent their identity by articulating their previous ‘normal’ childhood and adolescence; their cancer experiences; and an early survivorship identity (Jones et al., 2011). Such a process involves engagement with family, peers, and new people, which can be hard as teenagers report a decline of support after treatment, and many express feelings of isolation (Jones et al., 2011). This situation can be particularly challenging since adolescents are “a group that is developmentally focused on identity formation and peer relationships” (Jones et al., 2011, p. 5).

In overcoming her illness, Lorena constructed a new-normal identity (Cantrell & Conte, 2009; Gibson et al., 2016; Liu et al., 2015) by discussing topics that do not revolve around cancer. For example, she created the series “Careca’s Adventure”, where she plays online games, a peer activity that she can maintain despite her limitations with mobility. She is also shown interacting with friends and family members, as well as enjoying new relationships facilitated by social media, such as with other YouTubers and followers. As she moves into the survivor group and as her hair starts to grow she abandons the salutation “Hello, bald males and bald females” (01/04/2016) (even though the majority of her viewers are not cancer patients) and rather addresses her imagined audience with “Hello bald and hairy people” (01/06/2016). This process is full of ambivalence: Lorena sometimes referred to being bald as inevitable, yet at other times she talked about it as something that profoundly impacted her identity. She discussed in a video whether she will rename her channel BaldTV once her hair has grown back, going on to say she will not because that is part of her story and her identity (19/01/2017).

Through adopting a survivor identity, CarecaTV functioned as an environment where Lorena could engage in activism while connecting her cancer experiences and emotions with wider social issues, such as being a teenager in the Global South. For example, she selected hats to donate to a hospital that assists children with cancer, and invited viewers to donate pieces of clothing to homeless people (11/01/2016). On another occasion she posted about herself and other peer-patients playing in the children’s hospital playground to promote an awareness-raising campaign about the early symptoms of childhood cancer (13/10/2016). The YouTuber is also publicly affiliated with campaigns that donate hair to children with cancer (24/10/2016; 07/11/2016), and with the Ronald McDonald House in her hometown (2017). Crucially, CarecaTV is also a platform to engage with wider political issues. For example, Lorena raised the problem of equitable internet access in Brazil and collaborated with another YouTuber, Atila, by asking for a “#fairinternet” (29/04/2016).

Lorena has also used her channel to approach issues related to gender and health, such as when she discussed women’s reproductive rights and the Brazilian abortion laws in a video she recorded with her mother (03/12/2016). In this way, YouTube gives Lorena an opportunity to control and manage how she positions herself in society, not only as a patient or a survivor, but also as a citizen. Simultaneously, Lorena’s illness is symbolically constructed around private issues and entrepreneurial efforts. As Lorena becomes a microcelebrity (Abidin, 2015), her participation in social media is marked by public recognition as well as financial compensation, from the monetization of videos on the CarecaTV platform. Lorena is also affiliated with brands and products. For example, she has endorsed a brand of hair products by providing an account of their use and a review of their safety for people with serious illness, or for children with allergies. Additionally, she offered a discount code for her viewers to use when purchasing the products online (05/05/2018). Lorena used her social media visibility to fundraise and buy a car, as her family did not have one, and she argued it would help make her travels to treatment more comfortable (01/04/2017). Lorena also launched a book about her story – a practice that has become increasingly common among Brazilian YouTubers – and this was intensely marketed through her videos.
These entrepreneurial attitudes can be interpreted as one way to try to gain control over an otherwise unpredictable future (Stage, 2017), especially in a country where financial conditions for many families are challenging and for what appears to be a lower-middle-income family relying on a precarious public health system and not-for-profit organisations (Dixon-Woods, Young, & Heney, 2005).

Lorena has adopted a status of being ‘exceptional’, infusing her public visibility with affect, embracing her personal mission “to address social problems, needs, and solutions” (Stage, 2017, p. 47). Through her social media presence, Lorena’s transition from cancer treatment to survivorship results in a performance of a range of cancer identities which often coalesce with her promotion of normalcy and a projection of her ‘new-normal’ identity. While making sense of the paradoxical struggles involved in recovering from a serious illness, Lorena is inevitably influenced by her interactions in this networked environment, as well as by the media attention and public recognition. The next section uses this case study to advance a proposed framework to account for the complexity of the processes described.

A Proposed Framework

In contemporary societies where youth is increasingly mediated, the relationship between children and social media can be seen as both positive and negative, with a special focus on perceiving these as interacting (Livingstone, 2016). As CarecaTV has illustrated, this complex perspective also applies to the experience of sick children within these online spaces. Moreover, the experience should be constructed in a comprehensive way, where digital media is not considered a realm that is separate from everyday life. Rather, focus should be “on how new intersections between physical, mobile and digital spaces have the potential to impact children and young people’s wellbeing” (Swist et al., 2015, p. 23). This framework thus rejects the ‘effects’ paradigm (Staksrud & Milojevic, 2017) and adopts a focus on digital rights – an adaptation of the provision, protection, and participation rights of the United Nations Convention on The Rights of the Child in the context of the digital environment (Livingstone, 2016). Besides the right to access digital media, these intersections highlight rights to digital, media, and social literacy as providing a fundamental foundation for accessing, understanding, and participating in digital media creation and, thus, to exercising full communication rights in society. Interestingly, Lorena Reginato also dedicated one of her videos to call for attention to be given to securing a #fairinternet (29/04/2016).

From this perspective, sick children and their families can be empowered through health media literacy education (Higgins & Begoray, 2012) regarding their contact with health information shared on social media. Such education would help avoid any misinterpretation of individual circumstances and experiences, prevent an inadequate context in which to investigate the implications of a diagnosis, and assist in guarding against inaccurate or inappropriate medical treatments. Such literacy should also promote coping skills to support children who are faced with unwanted and harmful comments. It is important to review the ethics of sharing information or images of sick children on social media in terms of their rights to privacy, or to allow subsequent removal of content through ‘a right to be forgotten’, as may happen when a child is the author of his/her own social media visibility, and later regrets these activities when they are old enough to see them in an adult context.

As Lorena’s case exemplifies, children’s digital experiences across the world are affected by variations in digital environments that reflect “differences in language, geography, culture and power – as defined by the state, commerce or, most locally, family and community” (Livingstone & Third, 2017, p. 664). Therefore, sick children’s use of social media should be considered in relation to their multidimensional and fluid identities. Alper, Katz, and Clark (2016) argue for
the use of *intersectionality* in children and media scholarship so as to consider the “links between different dimensions of identity, different forms of inequality, and different ‘degrees of marginality’ (Murdock, 2002, p. 387)” (p. 108). Experiences of children who craft a media presence are diverse in relation to the advantages they might have in one dimension, and the disadvantages in others. In this regard, one could take an ‘asset-based’ rather than a ‘deficit-based’ perspective to identify “the abilities, agencies, and aspirations individuals draw on in order to address life challenges and opportunities” (Alper et al., 2016, p. 109), such as illness. Researchers and commentators analysing these instances of children’s digital media use should consider not only the impact of social and geographical inequality on the prevalence of disease, but also the different ways in which forms of inequality can affect how children and their families – and their country – cope with illness. These aspects may translate into differences in the use of social media for potential benefits, and to limit possible drawbacks during and after treatment.

Moreover, however transitional, illness can be seen as a challenge that defies the future hopes of the child and his/her family, and imposes feelings of vulnerability. Yet, at the same time, if it can be overcome, the illness can be taken as an opportunity and a journey which can be amplified through social media. CarecaTV demonstrates how a teenager used the advantage of her family background to establish herself as an entrepreneur and activist, while appreciating the online social support for her illness as well as facing the perils of unwanted commentary and trolling. While networked illness may counter the stigmatisation and isolation of sick children and contribute to an improvement in their psychological well-being, it may also “reproduce many of the biases that exist in other publics [such as] social inequalities, including . . . around race, gender, sexuality, and age” (boyd, 2010, p. 54).

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