

RESEARCH

Writing Letters to the Dead: Crippling Networked Temporalities on Social Media

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This article departs from the idea of *writing letters to the dead* as a way of crippling time in which ableist pasts and presents are uncovered and disrupted with the aim of changing the future for people living with disability. This is explored through the social media initiative *Dear Julianna*, which is analysed as a case of online disability activism and media representation seeking to confront conventional media narratives of disabled life courses by shifting the focus from a future of 'imminent death' to one of 'living' with disability. Building upon cripp and queer discussions of embodied notions of time and temporality, the article proposes a critical framework for challenging dominant understandings of disability in relation to time. In conclusion, it is discussed how social media have accelerated our perceptions of time in ways that complicate what we consider to be the opportunities and challenges of online disability activism. It is argued that while social media platforms may primarily be serving the interests of accelerating capitalist productivity, they might also facilitate new forms of temporal communities and ways of crippling time.

Keywords: crippling time; online disability activism; social media; Dear Julianna; writing letters; networked temporalities

Introduction: Rearticulating disability in relation to time and temporality

As a significant contribution to critical approaches to disability through the lens of ableism, Alison Kafer's (2013) work has demonstrated important links between ableist notions of time and the anticipations of disability as an undesirable and unviable position of living which is framed and addressed through the conceptualization of *cripp time* (Kafer 2013: 27; 34–40). Kafer's articulation of *cripp time* is defined as temporal reorientations of the particularity of disabled embodiment, thus offering a lens through which the primary conception of time is repositioned from its often mechanical and quantifiable properties towards the temporal qualities of subjective embodied experiences.

Driven by a profound critical intent to uncover the ways in which bodies and minds marked by disability often seem to be stuck in positions of failing conventional understandings of time, a central aspect of *cripp time* is to rearticulate the expected life course of living with disability, and thus to point out and contest the inherently ableist nature of normative scripts of time and temporality. In this connection, Kafer specifically mentions that 'writing open letters to the dead [surely can] be read as a queer *cripp* intervention of the linear time of past/present/future as separate and distinct planes' (ibid.: 42). This she exemplifies through the creative writer and disability scholar Georgina Kleege's fictionalized letters to the late author and disability activist Hellen Keller in the book *Blind Rage: Letters to Helen Keller* (2006). Kleege who in her writings criticizes and protests against Keller's position as an icon and representative of blind culture, both during her life and posthumously, is by Kafer placed as a critical confrontation of the past which, in its direct way of addressing the dead, becomes a strategy for *cripping time*.

In this article, I depart from the idea of writing letters to the dead as a way of crippling time in which ableist narratives of the past and present are uncovered and disrupted with the aim of changing the future. Particularly, this is explored in connection to online and social media which in recent years have become important sites of disability representation and arenas for entrepreneurial and activist voices from an emergent globalized disability community (Ellis 2016; Ellis & Kent 2017; Trevisan 2017). The aim of bringing together the concept of *cripp time* with disability activism on social media is to propose a critical framework for challenging dominant understandings of disability in relation to time, as well as to offer an empirical case-based analysis of the current landscape of disability media representation.

Analytically, I engage with the transnational social media initiative *Dear Julianna* which occurred in the fall of 2015 in response to a US American news story from CNN about Julianna Snow who was a 5-year-old, now deceased, girl with a neuromuscular disability (NMD). The *Dear Julianna* project, which was communicated as a publicly available letter writing campaign on the social media platforms Tumblr and Facebook, is analysed as a case of online disability

activism seeking to challenge conventional media representation of disability. Positioned broadly within a framework of cultural disability studies (e.g. Waldschmidt et al. 2017) and drawing on methods from visual culture and media studies, the letters are, first and foremost, understood as vital expressions of crip temporalities which critically contest ableist narratives by shifting the focus from a future of 'imminent death' to one of 'living with disability'.

Second, in relation to social media a common view is that our perceptions of time have shifted through accelerations of regular clock time, not only creating new ways of thinking about temporality through terms of 'flow' and 'circulation' but also stimulating important discussions about the crisscrossing of socio-cultural properties of time; either as possible developments of new dynamic and agentive positions (Hassan & Purser 2007), or as inevitable advancements of capitalist productivity leading to new forms of 'desynchronization' between different temporalities (Fuchs 2014; Kaun 2017). I conclude the article by entering into this debate in order to complicate what is considered to be the opportunities and challenges faced by online disability activism when, at one and the same time, new hegemonic regimes of networked temporalities and social media time are being contested and embraced.

Dear Julianna: A case of online disability activism and temporal community-making on Tumblr and Facebook

In late October 2015, the North American news channel CNN posted the first part of a three-part story headlined: 'Heaven over hospital' (Cohen 2015a). The story, which also had the subtitle: 'Dying girl, age 5, makes a choice' (ibid.), was about Julianna Snow, a five-year-old US American girl diagnosed with a type of NMD called Charcot-Marie-Tooth disease. The framing of the story focused on Julianna's parent's choice of promising her that she wouldn't have to undergo further hospital admissions if she experienced health complications caused by her condition, and by that letting her choose 'to go to heaven' instead (ibid.). On the following day, the initiative *Dear Julianna* emerged on social media with an open invitation to adult people living with various forms of NMD to write letters and submit pictures with their own personal stories about life with a neuromuscular disability which was, then, posted simultaneously on Tumblr and Facebook.

As an initiative carried out by a transnational disability community, *Dear Julianna* is an exemplary site of exploration into the advanced practices of online disability advocacy taking place on social media. As pointed out by disability scholars, this has contributed to the growth of claiming visibility and citizenship for disabled people (e.g. Ellis & Kent 2017; Sépulchre 2018; Trevisan 2017). In *Dear Julianna*, the importance of the online dimension, including the affordances of the specific platforms used, has a number of implications that are particularly pertinent in relation to discussions of time and temporality. It is, for one, of relevance to note that the initiators behind *Dear Julianna* managed to mobilize and to organize their project across different geographical locations in the US and Europe, and to launch it within a very short period of time which, as already mentioned, happened just one day after the publication of the CNN story. The swift coordination of *Dear Julianna* was only made possible by turning to online media communication and thus seems to illustrate the accelerated and connective nature of social media (van Dijck 2013) in which 'alternative protest communication' has come to exist alongside commercial and mainstream media productions and interactions (Poell & van Dijck 2015; Kaun 2017). However, as *Dear Julianna* developed, it also became obvious that the initial visibility, which was generated through a steady stream of letters that were posted every day during the first month, was decreasing. I will follow up on these observations later on through a critical conversation about *networked* and *social media time* (Fuchs 2014; Hassan 2007; Kaun 2017; Kaun & Stiernstedt 2014). For now, it suffices to say that the case initially caught my attention through its characteristics as a collective statement communicated online by a group of disability activists who were writing letters about their lives in critical response to a mainstream media story.

Although around 120 individual people contributed with their own personal accounts and different experiences of living with NMD, I mainly understand the *Dear Julianna* project as a unified public declaration of resistance taking its form as a cohesive counter-narrative to the CNN story. This is especially made clear through the formalized expression of writing letters, but also through a number of common themes and figures identified in the written and visual content of the letters, such as references to growing up, educational achievements and the use of mobility aids and respiratory support. In my analysis, I will get more into some of these shared themes as specific pointers to the ways in which *Dear Julianna* can be interpreted as a form of 'crip temporal community-making' operationalized as a strategy for crippling ableist notions of time through social media.

Empirical collection of online resources: ethics and methods

The empirical materials I draw on are primarily the digital letter posts which on a content-level consist of written text and images. Yet, I also refer to other background resources, such as the CNN news story about Julianna Snow (Cohen 2015a, 2015b, 2015c, 2016), and a two-part blog post from an online disability community comprising an interview with two of the initiators behind *Dear Julianna* (Disability Visibility Project 2016a, 2016b). These sources are included in order to contextualize the letter posts in the broader public debates surrounding disability media representation.

Choosing online sources as the focus of analysis has different implications, some of which relate to discussions of time, and some of which pertain to questions of ethics and methods when using online materials as data for analysis.

First of all, the location of *Dear Julianna* on different social media sites implies a temporal dimension that is conditioned by the designs and affordances of the specific platforms in the broader landscape of social media (Felts 2016). Here it is important to note the differences between platforms like Tumblr and Facebook, and how they each facilitate and promote distinctive ways of conveying the same content as it is in the case of *Dear Julianna*. Tumblr, which is a platform for *tumblelogging* or *micro-blogging*,¹ grants its users plenty of options with regards to customizing and personalizing the visible output of the interface, and thus allows for a substantial amount of control with the appearance of uploaded content. In contrast, Facebook has a standard visual design for its profiles and timelines which is identical for all users, but through its status as the social media platform with the absolute highest number of active users globally (Statista 2018), it offers a broader potential for circulation and visibility. From a time-sensitive point of view, the choice of having profiles with the same content on both platforms indicates an awareness of the distinctive types of presences offered by different social media platforms. Whereas the affordances of Tumblr allow for more particular (but also time consuming) modes of expression, which might seem more consistent with the idea of crippling regular timelines in a project like *Dear Julianna*, the promise of instant connectivity through Facebook plays an important role in creating a sense of vibrant and dynamic timeliness through the possibilities of being continually present and visible in many people's newsfeeds.

Another important issue regarding the choice of analysing online materials relates to the much-debated area of online ethics. Media scholars have noted that whole new contexts and ways of exploring human expressions and interactions have become available with the rise of the social internet (Ess et al. 2002; Markham & Buchanan 2012). In media and communication research, this has led to ongoing discussions about so-called 'gray data', which has been described as 'data that exist in the gray area between human subjects research and textual analysis' (Rambukkana 2019: 314), and which has sparked many difficult questions about how to approach online materials in ethically sound ways. Although I situate my analysis of *Dear Julianna* within a methodological tradition of cultural representation (e.g. Hall 1997), drawing on text-based and visual analytical methods (Rose 2016) in which I consider the data as cultural artefacts; as text in context, I do acknowledge the complexities of the ways in which the internet blurs the boundaries of 'public/private' and 'text/persons' (Markham & Buchanan 2012: 6–7). However, as is also noted by members of the Association of Internet Researchers (AoIR), online ethics are much more than a set of fixed practices and rules in which the codes of conduct are highly contextual and should be based on reflexive decision-making processes (ibid.: 12). In the case of *Dear Julianna*, all data is contrived in the sense that it is initiated, curated and made publicly available by a group of people identifying themselves as part of an online NMD community. Neither the images and written texts from *Dear Julianna* nor the secondary background materials have been gated by private membership accounts. On the contrary, *Dear Julianna* made an effort to promote their online presence through different social media platforms, as well as through voicing their intentions in the wider circles of online disability communication. Considering *Dear Julianna's* framing of the project as a form of public awareness-raising campaign, together with my cultural text-analytic orientation towards the project (rather than as a form of digital ethnography), I have not found that any formal ethical oversight, including obtaining informed consent from the members of the community, has been necessary for this particular context. Yet, I am aware that other framings and uses of the material could have led to other ethical conclusions, and that there are many different and conflicting opinions when it comes to ethical expectations and guidelines in relation to analysing online communication practices and materials.

I have approached *Dear Julianna* on a number of analytical levels which might best be categorized as a form of thematic close readings of the written texts and images, combined with elements of visual content analysis (Rose 2016). The thematic analytical framing expands on the ideas that were introduced at the beginning of the article through further reflections on crip time, which are operationalized analytically in an exploration of 'the figure of the dead child' and its connections to ableist narratives of acceptable ways of living. Visual content analysis, which is a method that traditionally has its focus on finding patterns by quantifying repeated occurrences in very large amounts of visual data (ibid.: 87), is brought into parts of the analysis as a way of identifying recurrent elements in the letters. However, the purpose of turning to this method is not to suggest that the quantity of certain components in the visual material represents some kind of objective truth. Rather, it has to do with finding useful ways of embracing the collective aspects of the individual images and written accounts in *Dear Julianna*.

The figure of the dead child

In Kafer's discussion of crip time, a central component is *the figure of the dead child* as a symbol of the ways in which not all people are inscribed in positive and desirable imaginations of the future (Kafer 2013: 2–3; 28–34). Whereas the

¹ *Tumblelogging* and *microblogging* are synonymous practices of using online blog media supporting mixed media content (e.g. images, written text, audio, links, video), often through limited formatting options. Postings may vary in length or content and are conditioned by the default settings of the specific platform. As the term *tumblelogging* is associated directly with the platform Tumblr, *microblogging* has become the more general term used (Rouse 2012).

figure of the child traditionally can be located as an allegorical figure of the future, this changes when disability enters the equation. According to Kafer, the disabled child turns into a trope of *unliveable life*, and ultimately *death*, as certain identities, bodies and minds are easily abjected and erased through a general acceptance of the ableist reasoning that no one wishes for a child with a disability:

[A]ny future that includes disability can only be a future to avoid. A better future, in other words, is one that excludes disability and disabled bodies; indeed, it is the very *absence* of disability that signals this better future. The *presence* of disability, then, signals something else: a future that bears to many traces of the ills of the present to be desirable. In this framework, a future with disability is a future no one wants, and the figure of the disabled person, especially the disabled fetus or child, becomes the symbol of this undesired future (ibid.: 2–3 – *emphasis as in the original*).

In *Dear Julianna*, the figure of the dead child is obviously present in the very premise of the initiative as a direct reaction to a story about a 5-year-old girl who was given permission to choose death as a consequence of her disability; a narrative which was further reinforced later on as Julianna Snow actually did die less than a year after the occurrence of *Dear Julianna* (Cohen 2016). However, this took place after *Dear Julianna's* online activities had ceased to continue. What is also important to note, in connection to the relationship between Julianna as an actual person and *Dear Julianna* as an activist media campaign, is that even as the naming of the online initiative makes the reference to Julianna Snow overtly explicit through its title, it does not appear as a personal attack aimed at Julianna Snow and her parents. Rather it is, as the initiators mention in an interview posted by the online disability community *Disability Visibility Project*, a question about how mainstream media choose to portray disability:

There are a few sources that do a decent job portraying people with disabilities. We have to battle decades if not centuries of stereotypes of the disabled that we're helpless and those of us with severe NMDs are all going to die. This is the myth most of society believes although due to life saving medical advances over the past few years people with NMDs are living longer into adulthood (Disability Visibility Project 2016b).

More than focusing on the individual case of Julianna Snow and her family, *Dear Julianna* positions itself as an attempt to create alternative narratives different from the one communicated in the CNN story for a broader audience of social media users. At the same time, it is also specifically aimed at other children with NMD and their parents which is stated in the short description of the project on both Tumblr and Facebook: 'Letters to Children from Adults with Neuromuscular Disabilities' (Dear Julianna, Facebook 2015a; Dear Julianna, Tumblr 2015a), and further in the blog post, the founders state:

We are putting our stories out there to connect with others who share our same stories, but instead of terrifying people with tragic endings, we are giving reason to celebrate the quality of our lives as people with disabilities – not suffering and living meaningful lives. Dear Julianna is a different, happy ending to a story that has been spun by our media as impossible to write (Disability Visibility Project 2016a).

In this sense, the naming of Julianna in the title of the project (as well as in the repetition of it in the opening line in each of the more than 100 letters) becomes a personification of the figure of the dead child as it is framed by the media rather than a personal targeting of a particular family.

Both Kafer's and *Dear Julianna's* references to the disabled child as a symbol of unliveable life resonate directly with a line of queer-theoretical discussions about how certain temporalities are connected to certain bodies and their potential future (Edelman 2004; Halberstam 2005; Muñoz 2009). In some of these discussions, the figure of the child is inserted to illustrate how heteronormative scripts of the future are closely connected to the probabilities of (biological) reproductivity and, in turn, how queer subjectivity is always left in positions of questionability, suspiciousness and without a future (Edelman 2004: 3). Consequently, the figure of the child becomes an allegorical ideal of the future, produced by 'compulsory heterosexuality' (Rich 2003), as well as of cultural imaginations of genetics, health and hygiene, and therefore – according to Kafer (2013: 32) – also has a direct connection to the positioning of disability as a failed image of the future. The figure of the child thus creates a generic and unmarked image of a child who is always already inscribed in privileged positions of whiteness, heterosexuality and able-bodiedness. This leaves other locations of identity and embodiment, not just invisible and marginalized but also deprived of genuine opportunities for achieving accomplished lives. As is also stated by one of *Dear Julianna's* initiators: 'a child with a severe disability is only seen as a future angel in heaven' (Disability Visibility Project 2016b). Nourished by the myth that a child's well-being is not compatible with disability, the figure of the child, in effect, becomes a 'dead child'. In other words, disabled forms of life are in the CNN story (and also in other mainstream media) being disqualified as a result of the ableist reasoning that not all lives are worth sustaining, especially not if the prospect is not to be cured, or at least to become *less* disabled. One of the many phrasings pointing to this in the CNN story read: 'Her [Julianna's] coughing and breathing muscles are so weak [...] she will likely end up sedated on a respirator with very little quality of life' (Cohen 2015b). This reasoning serves, then, as a further justification of the idiosyncratic valuation of disability as an automated legitimization of choosing death over life, and it is thus this recurrent ableist notion of disability that is being framed as highly problematic in *Dear Julianna*.

Shifting the narrative: Adults with NMD 'living happy and long lives'

The actual letters and pictures in *Dear Julianna* challenge the narrative from the CNN story in various ways. One of these is to present a clear shift in terminology which, instead of using language pervaded by 'death' and 'illness', uses a vocabulary highlighting 'life' and 'living'. This tone was already set in the first letter that was posted as a collective statement from the NMD community: 'We want you to know that there are lots and lots of grown-ups out there that were born with the same disability that you have. We want you to know that we are living happy and long lives! Some of us are even older than your parents' (Dear Julianna, Tumblr 2015b). Whereas the CNN story consistently reiterates phrases such as: 'dying of an incurable disease' (Cohen 2015a) and 'terrible quality of life' (Cohen 2015c), the letters in *Dear Julianna* are permeated by life-affirming wording: 'I know my disease is incurable, but I have stopped focusing on that, and instead focus on living' (Dear Julianna, Tumblr 2015c), or: 'living with a disability can be hard, painful and scary at times, but all the joy that life brings is totally worth it. Life is so beautiful' (Dear Julianna, Tumblr 2015d). This shift was even further established through continuous repetitions of hashtags such as #LifelongNMD, #LivingWithNMD and #StillHere. By reorienting the terminology from a mode of imminent death to one centering on the possibility of life as being potentially *happy*, *long* and *beautiful* therefore also becomes a specific approach to rearticulating the future.

However, the shift in language does not mean that experiences of, for instance, pain and distress related to living a life with NMD into adulthood are left unacknowledged or disregarded. The authors of the letters in *Dear Julianna* don't shy away from articulating the hardships and difficult challenges their lives with NMD also entail. This was also initially noted in the first letter from the creators: 'Hospitals are no fun, but they can make you feel better, so you can grow up like we have. Hospitals and wheelchairs and helpers and breathing masks are part of our lives, but they allow us to get older and do all kinds of fun stuff' (Dear Julianna, Tumblr 2015b). Many of the letters touch upon experiences of being hospitalized and receiving medical treatments that are described as painful and scary, but apart from empathizing with this as a shared experience of living with NMD several of these accounts also tap into themes about reorientations of time. As one person writes: 'A good life isn't defined as one without pain and suffering. There are lots of different ways to live that can make you happy' (Dear Julianna, Tumblr 2015e). Here 'different ways to live' mark out a potential requalification of life, which is temporally conditioned by adjustments to dealing with 'pain and suffering' as an ordinary part of living. Another person writes: 'As I grew up, I learned that I could do so many things, maybe not in the same way or as fast as others but I could still do almost everything I wanted to do' (Dear Julianna, Tumblr 2015d). Here it is suggested that time may be experienced in particular slow ways but is not an obstruction of self-realization. Most of the writers also comment on their own experiences with upbringings defined by time-limited prospects of living into adulthood: 'When I was a baby, my parents were told by some doctors that I wouldn't live past 2 years old, but guess what? I did!' (Dear Julianna, Tumblr 2015f) and: 'the doctors didn't think I would live to be more than four years old. Now I'm 71 years old' (Dear Julianna, Tumblr 2015g). Here again, the statements counter the plot in the CNN story which through their continuous repetition turns into a form of crip temporal resistance to the forecast of short-termed life expectancy as the only possible course of growing up with NMD. Through the many accounts of adult people pointing out that they have exceeded the anticipated durations of their span in life, the emphasis is relocated from death to actual processes of living.

'Keep On Breathin' On': Advancing the qualities of life through assistive aids and technology

In the light of the narrative shift away from death and dying in *Dear Julianna*, the purpose of reframing the expected lifetime of living with NMD is further expressed by addressing (and crippling) a number of themes regarding mainstream narratives of disabled embodiment. These also concern temporal rearrangements of ideas about what is conventionally considered to be limitations rather than regular living conditions. In the CNN story there is an incessant emphasis on the poor quality of life Julianna would meet if she was to survive which is, then, categorically linked together with 'enduring difficult treatment' and 'painful procedures', as well as affective renunciations of receiving life support: 'she hated the hospital, especially "NT", or naso-tracheal suctioning' (Cohen 2015a). The constant interlinking of negatively charged experiences of disability, through receiving medical services and being dependent on assistive technology, subtly creates a position in which treatment and assistive devices come to equal bodily limitation and failure. In *Dear Julianna* this position is being challenged by communicating other ways of thinking about quality of life through mobility aids and assistive technologies.

To this part, I have looked more into the visual imagery of the letters and have, through visual content analysis, identified some of the recurring visual features, such as the occurrences of assistive devices and respiratory support, and the ways in which these are being reframed. With the exception of a few letters, all of the posts in *Dear Julianna* include one or more pictures (265 images spread across 120 individual letter posts). Most of these are portraits depicting the respective author of a letter in which it becomes visibly clear that the majority of people writing the letters make use of a number of assistive devices and technologies. There is, for instance, a high frequency of individuals portrayed in wheelchairs (73%) in which a smaller part is also depicted using various forms of respiratory technologies (8%), including non-invasive breathing masks such as BiPAP (*Bilevel Positive Airway Pressure*) and CPAP (*Continuous Positive Airway Pressure*) along with surgery-related technologies through tracheostomy and the use of portable ventilators. There are also a number of other assistive devices present in the images such as walkers, leg braces and tricycles (14%).

First of all, this leads to establishing that mobility aids are indeed significant visual markers in the photographic depictions of living with NMD in *Dear Julianna* of which wheelchairs are the most obvious. As a visual symbol, the

wheelchair holds a particular iconographic status and has, if anything, become the hallmark of disability symbolism. This is especially manifested through the *International Symbol of Access* in which the well-known illustration of a white graphic figuration, depicting a person sitting in a wheelchair, placed on a blue square, has become one of the probably most emblematic visual codes for disability accessibility. Conversely, the symbol has also been a cause of controversy in the broader disability community because of interpretations of its reductive and static characteristics.²

In *Dear Julianna*, the symbol is, in fact, integrated as part of the project's logo in which the familiar pictogram is included in a re-appropriated version as a 'hand-drawing', placed on the top of a letter and reaching out for a red heart (Dear Julianna, Facebook 2015b). Together with the high number of people using wheelchairs in the pictures, this shows an acknowledgement of the wheelchair as a defining characteristic for people in the NMD community. Bearing in mind the disapprovals of the wheelchair as a reductive symbol and the commonly problematic connotations related to being a wheelchair user which is, for instance, illustrated by the use of diminishing language, such as being *wheelchair-bound*, it is noticeable that in *Dear Julianna* the wheelchair is instead highlighted as a form of 'differential mobility' (Sawchuk 2013: 413) in a positive sense. Apart from being highly visible in the pictures, wheelchairs are also mentioned in many of the letters in which they are framed differently than as a symbol of passiveness and instead become qualifying markers of having an active social life by providing access to getting educations and jobs, or doing sports and travelling. As is expressed in a letter: 'With the help of all this assistive technology [wheelchair, breathing machine, feeding tube] I went to college, got a degree, and then a job. Also, because I had all these machines, I was able to have lots of friends and live a very active life!' (Dear Julianna, Tumblr 2015h).

Correspondingly, respiratory assistive technology is also emphasized as ways of increasing quality of life, instead of being objects of restraint and pain as in the CNN story. Although it is just a smaller number of the images in *Dear Julianna* in which breathing masks and machines are visible (8%), an infographic illustration that was posted near the end of the active period of *Dear Julianna* informs that several of the letters refer to respiratory support (Dear Julianna, Tumblr 2016). Furthermore, the illustration also had the caption: 'Keep On Breathin' On', signposting that respiratory support is also positioned through a temporal framework of expanding the expected course of living with NMD. Similar to the reframing of wheelchair-use, the conjunction of assistive breathing technology and disabled embodiment is presented in much more life-affirming ways than traditional narratives about disability aids: 'I think of my bipap as my best friend. It is what helps me stay alive and well' (Dear Julianna, Tumblr 2015i). One person even reports that she has named her ventilator after the friendly service robot Wall-E, the title-character in an animated Disney/Pixar movie (Dear Julianna, Tumblr 2015j).

In *Dear Julianna*, wheelchairs, breathing masks and other assistive devices are thus refigured as the very tangible solutions to how it is possible to rethink and advance what quality of life means. This becomes clear when looking into the representation of assistive devices and technology. Yet, *Dear Julianna* does more than highlighting critical discussions about reversing the norms of how disability is being framed in the media. Clearly, the letters in *Dear Julianna* attempt to build up a pensive conversation in which stories of the past, especially through the figure of the dead child, are being confronted and rewritten. But maybe even more importantly, the letters – as a collective statement – present new possible paths for temporal community-building and shared ways of embodying time by effectively refuting the ableist, reasoning that time progresses in similar ways for everyone.

Networked and social media time: Accelerations as opportunities and challenges in online disability activism

In a further perspective on the online context in which *Dear Julianna* took place, I will now turn to a conversation about *networked* and *social media time* in relation to disability advocacy. This discussion opens up to current debates in media and communication studies about the different views on the temporal implications of accelerated networked media communication forms (Fuchs 2014; Hassan & Purser 2007; Kaun 2015; Kaun & Stierstedt 2014), as well as to the popular usage of commercial social media platforms in relation to activist and protest movements (Kaun 2015, 2017; Poell & van Dijck 2015; Uldam 2017). While the entanglement of social media and disability advocacy has, to some extent, begun to form an area of interest in disability media studies (Ellis & Kent 2017; Trevisan 2017), there still remains space for addressing questions of how temporal developments and rearrangements of social media and disability activism intersect and overlap.

In the existing media studies debates on social media and temporality there are, roughly speaking, two contrasting positions of relevance to my analysis of *Dear Julianna* in this article. While both of these depart from the premise that our common understandings of time have accelerated as a direct consequence of media technological developments, they differ in their interpretations of the outcome of such temporal escalations. The first version is that because

² *The International Symbol of Access* was originally designed for an international design conference held in Sweden in 1968 by Susanne Kofoed who was a Danish graphic design student. The criticisms of the symbol from disability activist communities have led to suggestions about updating the original symbol, e.g. by changing the posture of the figure to a forward-leaning position to indicate a more dynamic, active person. Others have also criticized the symbol for being prejudiced and reductive towards disabled people who are not wheelchair users (see for example: RI Global (sd.)).

time has become 'networked' (Hassan 2007: 46), understood as the connective and social modes of information and communication technologies, it encompasses a transgressive potential to destabilize mechanical clock time in ways that allow for people to connect *asynchronously* (ibid.: 51); for instance, through email across different geographical continents. In relation to *Dear Julianna*, this mirrors the possibilities of being able to connect transnationally and being allowed to plan and to organize the project, conceivably in different (bodily) paces. This position thus supports the idea that social media offer advantageous opportunities for disability activism in ways that support crip temporal embodiment.

In the meantime, the second position takes a more critical stance towards accelerations of time through social media because of the inseparability from capitalist productivity and commercial interests (Fuchs 2014; Kaun & Stiernstedt 2014). Here it is stressed that social media platforms, such as Facebook and Tumblr, increasingly demand their users' time and attention to produce and consume content which, in addition, help to sustain and reproduce economic inequality (Fuchs 2014: 119–120). Furthermore, it is claimed that social media restandardize our notions of time in ways where users suddenly have less control with the time they 'choose' to invest because they are elusively encouraged to spend as much as possible time on a given platform (Kaun & Stiernstedt 2014). Although *Dear Julianna* doesn't seem to be an obvious subject to commercialized logics, in the matter of its narrative content, it is also important to note that the actual production and distribution of the content is dictated, at least in part, by the logics of time on social media in which being persistently present and providing constant updates are rewarded with a higher visibility along with more followers and 'likes' (Kaun 2017: 471). As was also briefly mentioned in the introduction to the case, *Dear Julianna's* activities were most visible during the first month of the project due to the steady stream of letters that were posted every day. Then, during the following months, less letters were posted and eventually, they just stopped. Because the project was not officially announced over, the immediate interpretation could easily be that the message of *Dear Julianna* failed to stand the test of time. Here I would suggest, however, that it would be more accurate to say that *Dear Julianna* failed to stand the test of *social media time*.

What happened with *Dear Julianna* might best be described as a form of 'desynchronization', which media scholar Anne Kaun (2017) has conceptualized (with reference to the sociologist Hartmut Rosa) as a temporal conflict triggered between the logics of acceleration on social media and the political processes of activist movements. While social media rely on logics appreciative of expeditious renewal and constant presence (ibid.: 471), the quests for social change in protest movements often work through multi-layered timelines, sometimes involving slow and cumbersome processes of mobilization and development, such as organizing political agendas and handling administrative tasks (ibid.: 473).

Yet, the fact that desynchronization took place in *Dear Julianna* doesn't necessarily mean that the project failed to communicate their political message. Rather, the processes of desynchronicity, as well as the processes of asynchronicity, which allow the members of *Dear Julianna* to connect and to collectively carry out a crip intervention in the first place, point to the simultaneous opportunities and challenges when practicing disability activism on social media. This shows that while social media platforms may be serving the interests of accelerating capitalist productivity, they also facilitate new forms of temporal communities and ways of crippling time.

Conclusion

This article departed from the idea of writing letters to the dead as a strategy for crippling time by confronting ableist notions of past, present and future. Taking Kafer's conceptualization of crip time, including the figure of the dead child, I have in this article sought to build onto a critical framework for challenging dominant understandings of disability in relation to time and temporality. Within a framework of cultural disability studies, *Dear Julianna* was analysed as a case of online disability activism using letter writing as a critical approach to confront mainstream media's narrative framings of (early) death and disability as being inextricably intertwined. I emphasized that the letters in *Dear Julianna* served as a useful tool for crippling conventional media narratives through both the written and visual accounts which showed different ways of refuting and reorient ableist positionings of living with NMD. While many of the written statements in the letters pointed to a consistent shift in language in which the attention was relocated from death and dying to processes of living, the themes made visible through the content of the images pushed the discussion towards critically questioning established notions of what 'quality of life' means. In that connection, assistive devices and technologies, namely the wheelchair and variations of respiratory support, were accentuated as significant visual elements, illustrating other non-normative and embodied ways of living long and full lives. As a supplementary perspective on the online context and the accelerations of time on social media, I suggested that the differing positions of asynchronicity and desynchronization were concurrently present in *Dear Julianna* through which I concluded that several interrelated temporalities are balanced and negotiated in disability activism on social media.

Competing Interests

The author has no competing interests to declare.

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