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"Hey there in the Night": The Strategies, Dilemmas and Costs of a Personalized Digital Lobbying Campaign

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ABSTRACT This chapter analyzes the strategies and dilemmas of a digital storytelling campaign evolving around the plights and struggle of families with severely ill children in need of constant care. The campaign, organized by parents fighting to stop government cuts in health and welfare benefits, started on social media. Stories and pictures of the children soon went viral, caught the headlines of the national established news media, and impacted the political agenda. This parent initiative epitomizes newer trends in advocacy and lobbying in which citizens organize in ad-hoc campaigns and networks made possible by social media, and where compelling storytelling can outmanoeuvre established political actors. Social media and autobiographic stories provide effective tools for grass-root movements, but also pose a range of dilemmas and ethical concerns related to individual exposure, vulnerability and privacy rights. The focus here is how non-professional activists balance, negotiate or sacrifice privacy protection and control with their messages in the name of winning a larger battle where high personal stakes are involved.

KEYWORDS Social media, Campaigning, Health authorities, Patient narratives, Moral dilemmas

1 INTRODUCTION

Hey there in the night, Erna.
What are you doing?
Sound asleep in your bed I reckon, not worrying whether your child or husband is breathing or whether there is a cure for their condition.
What do I do?
Well, I'm on night duty, watching over my girl, who sleeps on oxygen because she cannot breathe properly, and wondering whether the healthcare service will find out what is wrong with her one day.
I also worry that I'm soon entering my final period with normal salary (100 % care benefit) and whether we, as a family of five, will manage when my income is reduced to 66 %. All our three kids are chronically ill and demand extra work, extra care and extra medical expenses.
How can we manage? Can you give me an answer?
(Mother Bettina Lindgren to Norwegian Prime Minister Erna Solberg, 17 September 2017)

In September 2017 a network of mothers of chronically ill children started posting heart-wrenching public letters to the Norwegian prime minister, the minister of health and the minister of labor on the politicians' Facebook walls. The mothers mobilized to protest suggested cuts in the Norwegian care benefit policy by documenting insights into the daily challenges they face looking after their gravely ill children. In the Facebook posts, the parents provide portraits of their suffering children – the children's interests, habits and personalities; close-up photos documenting their lives with bed-ridden, often hospitalized children – unmade beds, messy hair and drained faces; hospital equipment, probes and wires. Supplemented by texts written in a personal, direct tone – as open-hearted letters from one person (the parent) to another (the minister in charge) – these emotional Facebook letters from the sick beds of vulnerable children targeting responsible politicians quickly attracted massive attention, and the families' stories were covered by numerous established news outlets.[1] Over a few intense months, the parents formed a protest movement based on social media, mobilized broad political support, and convinced the political opposition to block two of three proposed government cuts in the care benefit system.

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1. Norwegian newspapers and broadcasters published about 380 stories addressing the proposed reform from September through December 2017 (based on a keyword search in the media archive Retriever).

Health protest groups and patient movements started challenging the power of medical elites and experts from the 1960s (Phil & Stephen, 2004). In this struggle, stories of lay voices and their personal experiences with illness became a central tool to oppose the authoritative medical regime and to expand upon what were regarded as legitimate public issues and forms of knowledge (Phil & Stephen, 2004). Experiences that were previously surrounded by silence, stigma and isolation were shared to create support and build new collective identities, transforming both the cultural understanding of diseases and how they were medically studied, prioritized and treated (Brown & Zavestoski, 2004; Brown et al., 2004; Klawiter, 2004). The rise of patient movements demonstrated that patients and their families contributed important insights and should be given a public voice, rather than treated as medical objects by expert classification systems and medical definitions from above (Frank, 2013). Today, many patient and health movements have grown into corporatized organizations with professional lobby expertise, dedicated communication departments and close connections to the medical field, pharmaceutical industry and government (Klawiter, 2004). Others remain on the fringes of established political channels and professional lobby networks, struggling to get disputed medical conditions accepted as legitimate diagnoses, or representing ad-hoc grass-root activism and campaigns operating without the organizational apparatus of the established professionalized movements – but also without the constraints of big complex organizations (Klawiter, 2004).

The *We are more than numbers* campaign represents a contemporary ad-hoc grass-root movement that epitomizes broader changes in the media landscape, changes in advocacy group strategies for political impact, and the power of personal, experiential narratives in contemporary political communication. With new communication technologies and platforms, ordinary people have gained opportunities to influence the form and content of news and public debates. Social media in particular represent an open, low-cost opportunity to provide information, mobilize supporters, raise funds, interact with multiple constituencies (Guo & Saxton, 2014; Lovejoy, Waters & Saxton, 2012; Vromen, 2017), and network with decision makers to achieve political impact (Figenschou & Fredheim, 2019). Extant studies of such personalized political communication and digital activism have largely focused on professional actors such as governments, interest groups or news professionals. An emerging literature on digital native citizen-based campaigns have studied the ability of these initiatives to profit from the affordances of social media, but not delved into the particular challenges and ethical concerns involved when autobiographical storytelling is used in political campaigning (e.g. Vromen, 2017). Non-professional political actors arguably face different challenges and dilemmas since they often fight for causes in which they are personally

involved. Based on qualitative interviews with a group of such activists, this chapter gives an in-depth discussion of the aims, strategies, dilemmas and personal costs involved in the highly personalized political campaign against cuts in the care benefit policy.

2 ANALYTICAL FRAMEWORK: PATIENT NARRATIVES ACROSS MEDIA

Archetypical human-interest stories are populated by victims and heroes struggling to overcome evil forces and re-establish justice (Langer, 1992; Gripsrud, 1992). Individual stories are essentially explanatory narratives incorporating cause-effect accounts that simplify the processes they explain, apportion credit or blame, and distribute individual responsibility (Tilly, 2008). Rather than through appeals to primary logic and evidence, stories are told to evoke emotional connections, identification, sympathy and community (Poletta et al., 2011). Stories claim to represent and understand, and those who have experienced a story first-hand are often given an authoritative, privileged position. The more a story is presented as a generalized or shared experience, however, the more that particular story's representativeness will be challenged by other interests (Shuman, 2005).

In established news media, the use of human-interest stories is often associated with professional ideology, changing media technologies and the commercialization of the mass media (Schudson & Andersson, 2009). In this setting, personal tales and intimate details have served the professional ideal of siding with the little man and simultaneously catering to a mass audience that secures economic revenue (Gripsrud, 2000). The use of such human-interest stories in health and social affairs journalism has been common, but contested (see among others Birks, 2017; Coward, 2013; Figenschou, 2017; Hodgetts et al., 2008; Karpf, 1988; Seale, 2002). Seale's (2002) in-depth study of health narratives is particularly informative for this chapter. Seale (2002) identifies a conventional plot where patients and their kin are given the role of suffering victims and battling heroes, faced by politicians or health bureaucrats who fail to provide the necessary treatment or care. Stories always contain evaluative elements intended to persuade the listener, and in the media the stories of patients and their kin have become the authoritative, entitled versions of events (Shuman, 2005). The media's need for victims with extraordinary emotional appeal tends especially to favour unambiguously innocent victims and worthy heroes (Höijer, 2004), the top of Moeller's (2002) mediated hierarchy of innocence. In the role of villain, the latter groups are described as lacking the moral character and strength to do the right thing due to negative qualities such as lack of empathy, callousness, cowardice or simply incompetence (Seale, 2002). The negative characteristics of the authorities that obstruct the access to proper

health care contrasts the idealized qualities of victims and heroes. Patients are portrayed as especially innocent and particularly brave and good humoured, in spite of their arduous situation. Their helpers (family, friends and local community) tend to be cast in an idealized light, one in which sacrifice, generosity, support, love and friendship juxtaposes the incompetent and narrow-minded decisions of responsible political authorities (Seale, 2002).

The tendency of the mass media to emphasize clear-cut morals, idealization and blame is often explained by the ability of such narratives to attract and engage a large audience. When storytelling is used by advocacy groups and campaigners, a similar strategy to reach out to ordinary citizens is involved (Thorbjørnsrud & Ytreberg, 2020). This style of campaigning has been successful against better-resourced and more influential opponents when stories appeal to a narrative moral urgency and 'people over power' as opposed to 'politics as usual' (Vromen, 2017, p. 127). To be appealing on the most basic cultural level, such stories must provide some type of hope and meaning, or else people will find them uncomfortable and depressing (Frank, 2013). In a media-saturated world marked by attention deficit and compassion fatigue, it is further argued that human-interest stories need to feature protagonists with a particular mobilizing power in order to attract and hold the interest of an audience (Orgad, 2013).

Personal stories, with their immediate appeal to emotions and engagement, have been claimed to be more important in the current hybrid media landscape than ever before (Beckett & Deuze, 2016; Wahl-Joergensen, 2016). Social media platforms are different from established news media on all three dimensions: *media production*, *distribution* and *use* (Klinger & Svensson, 2018, p. 5) of which the first two are of most importance here. First, on social media platforms all users and stakeholders can produce content; production costs are low as lay producers only need ordinary consumer equipment; and immediate, horizontal, interactive and individualized communication is privileged (ibid., p. 6). Second, social media have altered the way information is distributed – as users share information in their own information networks rather than via top-down distribution from one sender to a mass audience. The ideal here is viral spreading from user to user; shareworthiness has become increasingly important as social media platforms privilege popular items and influential people (Klinger & Svensson, 2018; van Dijk & Poell, 2013). Overall, social media platforms privilege attention over factual information, and a growing strand of literature underlines the importance of emotions for social media posts to be seen, shared and engaged with. Posts that trigger emotions such as hope, surprise or anger, tend to rise in popularity and reach larger networks (Hermida, 2014; Beckett & Deuze, 2016; Berger & Mikman, 2012; Kilgo et al., 2017), whereas sadness

does not necessarily increase the shareworthiness of a post (Kilgo et al., 2017). To engage such affective publics, 'social news' is often characterized by explicit positionality rather than striving for balance or objectivity (Hurcombe, Burgess & Harrington, 2018).

The potential impact of digital storytelling for networked online campaigns makes carefully constructed personal narratives an attractive organizational tool. Yet, scholars also point to the risks of storytelling tactics. Many storylines seem to create immediate engagement, but such 'short-term triumphs' do not necessarily lead to long-term change. Moreover, when poorly told, personal stories may discourage emotional identification rather than foster it (Poletta, 2011), and the legitimacy and representativeness of stories that travel far from the original source is often questioned (Shuman, 2005). Less often discussed in previous research is the potentially severe personal costs and challenges involved in running such personalized campaigns for lay activists.

On networked platforms such as Facebook, the individual user (in dialogue and cooperation with their network) bears the main responsibility for what she/he wants to share and with whom – their networked representation of self. Although Facebook (from 2015) warns against and removes graphic images and nudity, the social network has practiced a minimalist ethical involvement in which users who share emotional and private information have rather been strongly encouraged and promoted by the platform. For non-professional actors and activists, particularly those who use their own family, their personal life and experience, how to combine the role of parent and activist, and the problem of balancing voice vs. exposure, credibility vs. agitation, privacy vs. shareworthiness all raise a number of ethical dilemmas. The legal framework is ambiguous, aiming to balance several conflicting aims: privacy rights, copyright issues and freedom of speech for both the children involved and their parents. In essence, parents are obliged to act in the interest and needs of their children, and to seek to balance children's right of self-determination and involvement with their role as responsible caretakers (cf. the Norwegian Children's Act (1981) and the United Nations Convention on the Rights of the Child (1989)). Overall, children's rights to privacy on social media has not been addressed specifically in the existing legislation, leaving room for the parents/activists to find the right balance for their individual case.

At the same time, personalized networked campaigns initiated by non-professional actors, do raise both legal and ethical dilemmas for the professional actors and institutions that are directly involved in or confronted by the personalized criticism (Figenschou & Thorbjørnsrud, 2018). For established news

organizations, working with and on patients' personal stories can challenge ethical codes[2] since these narratives can test the professional balance between empathy (to listen and understand), engagement (to get involved in the story) and distance (to keep a critical overview) (Glück, 2016; Larssen & Hornmoen, 2013). Moreover, press codes place a particular responsibility on journalists to protect vulnerable individuals who are unable to give informed consent against potentially harmful exposure (Larssen & Hornmoen, 2013). Such ethical considerations are particularly pressing today as established news media increasingly both distribute and find news stories on social media platforms and *shareability* has become a key news value in contemporary news production (Harcup & O'Neill, 2017). For political and medical authorities, privacy laws and principles of confidentiality in operational activities must be respected. Public authorities can neither freely comment on individual cases nor present solutions that are not anchored in due policy processes (Figenschou & Thorbjørnsrud, 2018). Professionalized interest groups and patient organizations are responsible for acting in the interest of their members – as public authorities, they must attend to privacy laws as well as prepare and brief those individuals who represent the organization in public debate (Thorbjørnsrud & Ytreberg, 2020).

3 METHOD

Aiming to study how the instigators behind the *We are more than numbers* campaign reflect on their goals, strategies, dilemmas and constraints, we have conducted qualitative in-depth interviews with the organizers of the protest group (the mothers who organized the Facebook campaign and Snapchat account) involved in the start-up of the campaign. Together, these five mothers turned activists have professional backgrounds from blogging, publishing, social work and the health sector. These are skills and competencies that have enabled the campaign.[3] The semi-structured interviews lasted between 70–90 minutes each and were conducted by one interviewer in the interviewees' private homes in 2018–19. All interviewees were asked the same core questions about social media campaigning, lobbying, their personal engagement and the cost of this engagement: their

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2. The code of ethics is a set of normative guidelines adopted by the Norwegian Press Association (current version is from 2015).

3. We also conducted background interviews with one mother and one father who were featured in the campaign, but these interviews are not quoted in this chapter as they are not among the instigators of the campaign.

involvement in digital campaigning (awareness-raising, community-building, mobilization), lobbying (argumentation, strategies and process), being in the media (pitches, interviews and interaction with journalists) and the ethical issues and costs of running a personalized digital campaign (how to balance private vs. public, factual vs. emotional, efficient vs. considerate). All interviews addressed these core topics, although the order of the topics, the emphasis on various topics, and the additional discussions raised were adapted to each interview conversation, enabling the probing of relevant experiences, perspectives and dilemmas brought up by the interviewees. Many of the issues discussed were sensitive and challenging, particularly the questions on ethical dilemmas and costs, but the interviewees answered and reflected openly on all questions. All direct statements used in the analysis have been approved by the interviewees. All interviews were recorded, then transcribed by a research assistant. To preserve the interviewees' anonymity, we do not use their names.

The study is conducted as part of a larger research project on media, health and power in a hybrid media landscape.[4] Both authors have followed the Facebook campaign since the start and read transcripts of all parliamentary debates on the issue, as well as the news coverage on the campaign. Both authors read all interview transcripts and coded for strategies, evaluations, cost and dilemmas. Hence, both authors know the empirical data in detail – the interviews they conducted themselves and those conducted by the other. In this chapter we focus on the interviewees' reflections on the rationale and dilemmas of personalized advocacy campaigns in a networked media system.

4 ANALYSIS

The campaign was initiated at a bedside in a children's room just after midnight on 17 September, 2017 with the open letter to the prime minister outlined at the beginning of the chapter. In the days prior, parents of chronically and severely ill children had engaged in long discussions of the consequences of the proposed government cuts to the care benefit system in closed Facebook groups. According to the interviewees, these groups served as support networks and communities for the parents, an important 'backstage' arena and a community where the parents shared personal frustrations, worries, anger and pain with others in the same

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4. The Health Communication Regime project (2016–20) (https://www.samfunnsforskning.no/english/projects/health-communication-regimes-hecore-eng.html).

situation; asked each other questions; exchanged strategies; and expressed support for those going through particular hardships. In these closed groups, concerns about the planned cuts in the care benefit policy intensified in the weeks before the campaign launch.

The idea of organizing a protest had been debated, but fizzled out. According to the mother who initiated the open Facebook group it was a spontaneous expression of frustration and despair:

> I sat watching over my daughter who was ill, on oxygen to breathe. Took a selfie and wrote a quite sarcastic post to the prime minister – asking her how many worries she had. I believe it is extremely unfair that politicians can make decisions over the heads of those that are affected. I was actually pretty pissed off … I knew it would make some waves, because it shows a little girl who is hurting and also because of the tone of my writing. But [I was not expecting] this … (Mother3).

In addition to herself, she added six of the mothers who had been most vocal in their internal discussions as administrators to the group. Within days, all but one of them had shared similar open Facebook letters directed to and tagging the prime minister and other government ministers.

According to the interviewees, the primary aim was to document, exemplify and bear witness to the hardships and challenges of caring for chronically, seriously ill children and how they would be affected by the proposed cuts. They wanted to show the harsh realities of their lives – what was going on inside the operating theatres, inside the bedrooms and the many homes that have been turned into 24/7 "professional care units". The aim was to document that "what looked good on paper would have grim consequences", to alert responsible political decision makers, interest groups, the media and the broader public. One of the mothers further underlines that it was a particular ambition to demonstrate how it affected *the children* in order to reorient the debate back to those it concerned:

> The proposed policy was so focused on the parents, to reemploy the parents and get them back to work, and the consequences for the seriously ill children and their needs had crumbled away. So this has been important to me, to bring the children's voice into the debate – after all – this arrangement is for them (Mother4).

4.1 STRATEGIC AND PERSONAL: ARGUMENTS FOR A PERSONALIZED CAMPAIGN

To catch the attention of politicians, the media and the broader public, the mothers used what they perceive as dramatic but necessary means.

First, it was imperative for them to evoke emotions, to reach stakeholders and supporters by arousing feelings of anger, shock and moral condemnation. One of the mothers explains this strategy in the following way: "There are no better means to gain attention, in my view, than sharing photos to document the harsh conditions many of these kids and their families live in, combined with a completely honest, emotional text and some facts" (Mother3). These principles were central when the initiators of the campaign contacted the political parties, members of parliament, patient organizations, national newsrooms and local media. It was deemed important to reflect the gravity of the cause, as one of them explained: "These emotions are real emotions, because it is incredibly tough to live in these situations. That is the information we want to convey to people, for them to understand that it matters" (Mother4).

The interviewees are very aware of the mobilizing power of the cause they represent, fighting to protect young, seriously ill children. As they see it, that was among the main reasons the campaign made a political impact: "It is a cause that, when people hear the personal stories and the consequences for real families – it touches them. So we feel we have been backed by popular opinion throughout the process… These are compelling stories, because of the gravity of the situation of these children" (Mother1). One of the instigators takes on a more strategic approach, explaining the same mechanisms:

> It sounds harsh, but sick children 'sell'. It is perhaps our strongest card because we can share our stories and others share theirs. This way we have managed to create massive engagement, likes and shares… It evokes strong emotions because it is unfair and affects young, helpless, innocent children – who cannot stand up for themselves. It is us, the parents, who have to fight for them. And when the government proposes a new policy that weakens our rights to do so and force us to choose between caring for our sick children and our jobs… It is brutal, and everyone who has their own children think that 'this is not how we want it' – to leave kids alone when they are suffering the most (Mother3).

Second, many of the families affected by the policy have children with rare conditions, and personal accounts were used to contribute openness; awareness-building

and information-sharing about these conditions was seen as the key to informing politicians, the media and the general public. Consequently, the Facebook group became a platform to collect and publish multiple personal accounts from parents with sick children around the country. For families in this situation, a sense of community becomes particularly important. One interviewee explains how she finds meaning in sharing her family's struggles, because she found tremendous comfort and support from others' openness when her child was first diagnosed:

> I made the choice to be open a long time ago, which I believe is important! I started with me Googling his disease and I came across these other parents online. I just sat there reading, it felt so good, and although their situation was not identical, we shared a lot in common. And it was great to know that there was someone out there. I will never forget the feeling the first time I came across the stories of other parents of children with a similar condition as my child… (Mother5).

Interviewees highlight strong visuals as a necessary means to document the hardships of living with and caring for seriously ill children. Asked to elaborate on what makes a photo compelling in these cases, one of the mothers put it like this:

> A strong photo makes your heart stop for a second. It is a photo that can make you cry, that you find moving or you find to be terrible. A photo that documents the reality – what happens in the operating room behind those automatic doors. … People need to see it to believe it. People must be able to bear seeing what we live with every day. What they see photos of is how we live … The photos also need be of a certain quality – you cannot post blurry, poor photos. It has to be catchy and clickable, even in smaller formats (Mother3).

Third, the interviewees see the personal angle as a more honest and authentic contribution to the policy debate from their position as parents. This position of experiential legitimacy is explained by one of them in these words:

> I believe it is important, when you seek to convince others and argue for your case, that you speak from a position you know and understand. I am very good at being my child's mom, so I can speak as his mother. I can talk about my experiences … I can talk about my experiences with the old and new system. … I speak from this position as his mother, and if I take this position, I cannot be challenged and criticized (Mother2).

Others stress that they seek to convey the authentic perspective and voice of their children, because "these kids have no voice, they have been hidden away and forgotten for a very long time" (Mother3). In the Facebook campaign, writing in the voice and perspective of the children became a strategy in addition to the first-person accounts of the parents. One of the mothers who had written numerous op-eds and more factual posts says that writing in the voice of her son was what really engaged her readers and spurred the interest of the national media in her case:

> I wrote the open letter from my son's perspective, and it hit a nerve. I do not know if parliamentarians and decision-makers have read it, but it received a massive response on Facebook. And I believe this is because it is difficult to understand how these seriously ill children live their lives, until you see it spelled out: How it is to be little and to go through all these things that you do not understand and are forced to go through. Procedures that most people do not even know take place in hospitals (Mother4).

Fourth, the campaign has systematically targeted politicians directly, through personal appeals. As illustrated in the beginning of this chapter – the campaign started by an open letter written to the Norwegian prime minister Erna Solberg, addressing her as a mother by her first name. The interviewees see this strategy as crucial to get the necessary public attention to launch the campaign, as explained by one of them: "The media picked up the story very rapidly, probably because we targeted the prime minister directly and the letter caught huge attention. This led to stories in both local and national news media" (Mother1). Another interviewee explains that they tagged the prime minister in the angriest posts, but that tagging opposition politicians was equally important for political impact: "Erna was targeted because she is the prime minister. I believe we tagged her when we really had something to say!" (Mother4).

 The flipside of this direct personalized campaigning was that it might have turned the government against their cause after several ministers came under such individualized pressure. These statements demonstrate this perception:

> The government – the ministers and the prime minister – definitely had their version of this case. We do not feel that they listened to us, we actually got the impression that their policy became a matter of prestige, or that [the government] was caught by surprise… They did not respond to our criticism and rather highlighted how the reform benefits others – and that is not what

we were arguing against – we completely agree that more parents should receive care benefits. So we feel they were talking over our heads, besides our points … It is more interesting to notice what the prime minister *does not* talk about – politicians' 'empty answers' (Mother1).

4.2 MORAL DILEMMAS: BALANCING IMPACT, EXPOSURE AND PROTECTION

As demonstrated in the previous section, the interviewees' choice of a personalized campaign was aimed to serve multiple purposes. At the same time, the mothers faced a number of dilemmas regarding how to balance their roles as protective parents with that of a political activist. A key issue here is how they handled their families' – particularly their children's – need for privacy when involved in a personalized political campaign. As lay activists outside established organizational frameworks, these parents acted independently of professional guidelines and ethical codes. Moreover, current legislation on parental responsibility does not explicitly address exposure in social and news media. Hence, there is a lack of established practices and considerable room for manoeuvre on these issues.

   An initial finding here is that the interviewees saw the degree of exposure and privacy as a choice for each individual family. Each of the families/parents involved have set their own boundaries for how much of their private struggle they make public, and how. Many of these dilemmas concerned the use of photos and video, and some key considerations are shared among the interviewees: Overall, although they shared insights into their personal lives, they still kept most of their daily life away from the public eye. One of the mothers explains it this way: "I have kept my private relations out of the media. It is beyond the subject matter, and I find it very important to stay on topic. … To protect what needs protecting" (Mother2). Another elaborates: "There are costs associated with laying bare our private lives, but this does not mean that people know me. I do not unpack my entire life, I give insights into this particular situation for people to understand" (Mother4). Moreover, although raw emotions are deemed necessary to convey the hardship they are in, the interviewees are more careful regarding how the children are portrayed than how they themselves are presented. In several of the interviews, the mothers explain how they have laid bare their own anger, tears, frustration and exhaustion on social media and to news reporters. For the children, on the other hand, they are more protective.

At the same time as the interviewees are all very protective, they have ended up choosing different degrees of openness around their children's illness. Three of the mothers represent a more restrictive approach, which means that they originally aimed only to show their children outside of the hospital setting. This quote illustrates this position: "I have not documented when he is scared and most vulnerable. I have photos of him in the hospital bed, but not graphic ones … Images are a compelling medium, and I have not posted the 'worst', but rather selected some photos for publication" (Mother4).

As demonstrated in the following quote, however, the restrictive families/parents often ended up also including some photos of their children in treatment as the campaign evolved:

> We have been more restrictive than others but have at the same time shown more than we originally thought would be necessary. So that is something to ponder, and you do not know whether the balance is right until later, when you get this gut feeling… We would rather use photos of [our daughter] from her daily life – not how she is when she's ill. But we have shared this one photo of her in hospital, and that is the only one we use, although we have many. Others share a lot more, but this is what is right for us – based on gut feeling and conversations between me and my husband (Mother1).

This practice of selecting one symbolic photo of the child in treatment/hospital for public use was chosen by a couple of the more restrictive interviewees as a compromise between the strong need for protection and the need to make an impact. Other interviewees expose more – they zoom closer and document the suffering and pain – because they strongly believe that the end justifies the means. Here, too, the motivation is to do what is in the children's best interests, as illustrated by these statements:

> I have fully exposed my life. But then again, if the kids should confront me about why they are on my blog and social media, I will explain to them that I did everything I could with all means available to change this policy. I can justify it for myself and for them (Mother3).

> I ask my son permission. I continuously ask him throughout whether it is ok that we do this. It is important that we fight!… I inform him before reporters come that they are going to take photos or film. I ask him if it's OK. He agrees. I ask him if he likes being a star – and he nods again. So we have these talks.

> … I have informed the children that I'm doing this to fight against those who make the decisions in this country. Because I decided a year ago that even though I do my best to protect them and not discuss these issues in front of the children, sooner or later it will slip through. And then I need to prepare them and explain why I'm doing this in advance (Mother5).

In these cases, the mothers emphasize that they routinely ask their children to give their consent before publishing, but at the same time they explain that there are some published photos that are too brutal for their children to see. This could be images of the children in pain, when they are miserable and sad, or of situations where the children were unconscious. The mothers also protect their children from seeing photos documenting themselves in panic-stricken, disturbed conditions:

> [T]here is one photo that I have not shown him because I do not want to remind him, it is too painful. It is a photo of me crying sitting next to him… It was in the midst of a very helpless situation. It was a photo saying like, 'I've forsaken so much – I have no filter left' … I believe that I'm paving the way through the system, and I want this path that I make to be wide for others to follow (Mother5).

Also those interviewees who exposed the most say that they gradually revealed more during the process. One of the driving forces behind the campaign put it like this:

> Sometimes I publish without asking the children's approval, quite simply when there is a photo that is important to publish … that I do not want them to see of themselves… If they have been ill, but do not know how dramatic it looked, or photos of them in distress. We have intentionally taken photos in these situations, for documentation. We would not have done this before the campaign, but now I ask my husband or others, even nurses, to photograph… We need this documentation for them to believe us! (Mother3).

What this quote also exemplifies is that although the parents have a policy to always get the children's consent, the roles of parent and activist sometimes collide – the mothers publish photos of the children and themselves in distress, and at the same time avoid their children being able to see them. To find a balance they can live with, it is vital for all interviewees to hold on to a feeling of being in *control*. This also becomes clear in their relations with professional journalists. It is

routine for all of them to secure the right to read and correct any information about their children before publication. Some, though not all, have further negotiated the right to choose and approve all photos published of their children.

Among the interviewees, some express concern that too much suffering can undermine the cause in the longer run, a sort of compassion fatigue. One interviewee explains:

> You need the strong headlines … – the honesty and the shock effect – but at the same time you cannot overstate the pain because in the end people will skip and ignore the message. They might not want to be involved, they might not want to see it … Becoming repetitive is a risk – we who live with sick children are used to these explicit images – but then again we are not the target audience, we are not those who need to be convinced (Mother2).

How to keep the campaign going over time was a concern for all interviewees, but the most common approach was to seek new platforms and forms to continue a raw, personal narrative (such as launching a Snapchat channel in early 2018), rather than the (self-)criticism expressed in the quote above.

Whether it is ethical to expose children with grave conditions and illnesses has been a key criticism against the campaign. The campaign instigators have thus prepared a standardized response to such criticism in social media underlining that each family set their own boundaries and choose how much they want to share. Criticism voiced by healthcare professionals has made a particular impression on the interviewees. Some of the interviewees are provoked by the criticism against showing photos of sick children in social media as they see this as an example of stigma and double standards:

> When it comes to debating the exposure of seriously ill children – this pisses me off – because [if we cannot show sick children] then I can never show photos of my son… It is one thing to be against exposing children in social media in general, but that people approve of me posting a photo of my adorable little daughter jumping and playing around. And then the same people react when I post a photo of my beautiful son lying on his bed with a hole in his throat? … He needs to be out there too; he should not be hidden away in a closet like physically disabled kids have been for so long (Mother5)

She further explains that she has been contacted and thanked for her openness by other families who feel less alone, and by disabled adults who lacked such openness growing up.

Throughout the interviews it is evident that finding the right balance between the roles as parents and activists has been difficult. The point of departure for the instigators behind the campaign was a situation characterized by an extraordinary burden and concern related to their care for their children. Their deep involvement in the campaign (although this varies across the group) – the coordination, publishing, moderation, meetings and media appearances – comes on top of an already strained situation. Beyond their own well-being, those families with several children express unease with regard to how it will affect the children's siblings. One aspect of this is how to prepare and protect the siblings against seeing what is published about their sick sister/brother, as illustrated by this quote:

> I believe that the fact that we have come forward, or laid bare, ourselves and not the least our children – I believe it has made a difference. Obviously, it has been very difficult to do this. Particularly for those children who are old enough to understand what is written. My daughter is still so little, and she may never, really understand, but her siblings will be able to read the blog and the media stories when they grow older. (Mother1)

In addition, the interviewees worry that the campaign takes up too much of their attention and time, as illustrated here: "This fight has also impacted on his siblings, because in periods with heavy workloads I have been constantly on my laptop, cell phone in my other hand, in addition to numerous meetings. In these most intensive periods the cause has taken much attention, in addition to the fact that their little brother always needs special care" (Mother4).

5 DISCUSSION AND CONCLUSION

This chapter has analyzed the strategies and dilemmas linked to personal storytelling as a strategy employed by lay activists to repeal cuts to social security policies. The digital networked campaign *We are more than numbers*, initiated and carried out by mothers in families with severely ill or disabled children, took advantage of the new opportunities and affordances of social media, which enable people to organize, connect and spread their messages (Klinger & Svensson, 2018; Vromen, 2017). Thus the campaign exemplifies new trends in advocacy and lobbying in which citizens organize in ad-hoc networks made possible by social media and where compelling, personal storytelling can outmanoeuvre more established and professional political actors and interest groups (Guo & Saxton, 2014; Lovejoy, Waters & Saxton, 2012; Vromen, 2017). Such strategic storytelling has increasingly been taken up in political campaigning and by grass-root movements that

adapt their activities to a hybrid media landscape in which stories on social media spread to the established media and back again (Chadwick, 2013).

As elaborated in this chapter, the mothers/activists strongly believe that the campaign is in the best interests of their children. To a large extent, concerns over potentially negative exposure comes second for them. The aim of winning the fight for economic security – which for them assumes existential dimensions – justifies the means. In addition, some object strongly to seemingly well-intentioned advice from others/outsiders to shield their children from the public eye. To them, such concerns implicitly promote stigma concerning disability and illness, and publishing pictures of their children becomes part of a strategy to normalize their condition. At the same time, all the interviewees have limits to the extent to which they expose their children in the public realm. They have different perceptions and policies regarding how much, how close and what kind of images, videos and messages they publish of their children and family. What they share is an emphasis on *control*. The parents strongly emphasize the importance of controlling all the details of their messages, their timing, their wordings – and their images. This control remains vital to them even if they seem to have somewhat expanded the boundaries of what was shared during the process. Most interviewees ended up sharing more and zooming in closer as the campaign intensified, which illustrates the challenges of being both a parent and a political campaigner.

Combining lay activism with family life and professional obligations is resource-demanding, time-consuming and straining. The mothers/activists had somewhat divergent views on how to take the campaign forward: Some had intensified the sharing and openness by launching a Snapchat channel about life with chronically ill and disabled children. Others, worried about compassion fatigue, chose a more private, secluded life in order to protect their family and to make more of an impact if and when they had to mobilize again. The mothers' strategic and heart-wrenching openness raises a number of ethical issues regarding children's privacy, self-determination and right to protection from public exposure. Today there seems to be a grey zone rather than a clear line of demarcation with regard to how children's right to privacy should be defined – either as a matter of parents' best judgement, or as a field for legal regulation.

For the established news media, the exposure of vulnerable individuals on social media causes particular professional dilemmas. On one level, the interviewees found meetings with the professional reporters challenging because this forced them to let others tell their story and represent their children. For the parents, this involved a loss of control that most of them minimized through detailed agreements with reporters about the right to review and approve headlines, photos,

quotes and factual information. However, for news reporters, the press code places a particular responsibility on journalists to protect vulnerable individuals who are unable to give informed consent against potentially harmful exposure, regardless of how their parents judge the situation. In campaigns on social media, in contrast, there is no press code in effect. Hence, when the children's legal guardians are both protectors and activists at the same time, this can alter the established news media's professional balance between empathy, engagement and distance (Glück, 2016; Larssen & Hornmoen, 2013). The fact that most interviewees perceived the media coverage of the campaign very much in line with the campaign's agenda and framing indicates that the media largely magnified the campaign message to a broader audience rather than questioning, nuancing or bringing in new angles. As such, news stories served to extend the reach of the campaign, and news stories about the campaign were routinely fed into the social media campaign in order to demonstrate agency and impact.

In the current news landscape, where shareability has become an important news value, such compelling, emotional initiatives are more likely to gain massive exposure in both social and established news media. How the media should best cover such viral social media stories (characterized by emotions, positionality and personal narratives) evokes a number of questions: Should they report these classic victim-against-system health narratives, or should they protect the privacy of these children and their families? Could they, if they cover the campaign, indirectly push the parents/activists to expose more than they are comfortable with? Are such personalized social media campaigns pushing the boundaries of what is deemed ethically responsible reporting? And more fundamentally, how can such social media and media campaigns impact on the priorities and practices of health politicians in the longer run? This chapter has primarily focused on the strategies, dilemmas and costs of the parents/activists, but we hope that these overarching ethical issues regarding how such campaigns are dealt with by professional news organizations are investigated in future studies.

REFERENCES

Beckett, C. & Deuze, M. (2016). On the role of emotion in the future of journalism. *Social Media + Society*, July-September 2016, 1–6. doi: https://doi.org/10.1177/2056305116662395

Berger, J. & Milkman, K. (2012). What makes online content viral? *Journal of Marketing Research,* 49(2), 192–205. doi: https://doi.org/10.1509/jmr.10.0353

Birks, J. (2017). 'Moving life stories tell us just why politics matters': Personal narratives in tabloid anti-austerity campaigns, *Journalism,* 18(10), 1346–1363. doi: https://doi.org/10.1177/1464884916671159

Chadwick, A. (2013). *The hybrid media system: Politics and power.* Oxford: Oxford University Press.

Coward, R. (2013). *Speaking personally: The rise of subjective and personal journalism.* London: Palgrave Macmillan.

Dijck, van. J. & Poell, T. (2013). Understanding social media logic. *Media and Communication,* 1(1), 2–14. doi: https://doi.org/10.17645/mac.v1i1.70

Figenschou, T. U. (2017). Patient narratives: Health journalists' reflections, dilemmas and criticism of a compelling journalistic tool. In B. K. Fonn, H. Hornmoen, N. Hyde-Clarke & Y. B. Hågvar (Eds.), *Putting a face on it: Individual exposure and subjectivity in journalism* (pp. 235–256). Oslo: Cappelen Damm Akademisk. doi: https://doi.org/10.23865/noasp.28

Figenschou, T. U. & Fredheim, N. A. (2019). Interest groups on social media: Four forms of networked advocacy. *Journal of public affairs.* doi: 10.1002/pa.2012

Figenschou, T. U. & Thorbjørnsrud, K. (2018). Mediated agency, blame avoidance and institutional responsibility: Government communication in a personalised media landscape. *Scandinavian Political Studies,* 41(2). doi: https://doi.org/10.1111/1467-9477.12117

Frank, A. (2013). *The wounded storyteller: Body, illness & ethics.* Chicago: The University of Chicago Press.

Glück, A. (2016). What makes a good journalist? *Journalism Studies,* 17(7), 893–903. doi: https://doi.org/10.1080/1461670X.2016.1175315

Gripsrud, J. (1992). The aesthetics and politics of melodrama. In P. Dahlgren & C. Sparks (Eds.), *Journalism and Popular Culture* (pp. 84–95). New York: SAGE Publications.

Gripsrud, J. (2000). Tabloidization, popular journalism and democracy. In C. Sparks & J. Tulloch (Eds.), *Tabloid tales* (pp. 285–300). Landham: Rowman & Littlefield.

Guo, C. & Saxton, G. D. (2014). Tweeting social change: How social media are changing nonprofit advocacy. *Nonprofit and Voluntary Sector Quarterly,* 43(1), 57–79. doi: https://doi.org/10.1177/0899764012471585

Harcup, T. & O'Neill, D. (2017). What is news? *Journalism Studies*, 18(12), 1470–1488. doi: https://doi.org/10.1080/1461670X.2016.1150193

Hermida, A. (2014). *Tell everyone: Why we share and why it matters*. Canada: Random House.

Hodgetts, D., Chamberlain, K., Scammell, M., Karapu, R. & Nikora, L. W. (2008). Constructing health news: Possibilities for a civic-oriented journalism. *Health,* 12(1), 43–66. doi: https://doi.org/10.1177/1363459307083697

Hurcombe, E., Burgess, J. & Harrington, S. (2018). What's newsworthy about 'social news'? Characteristics and potential of an emerging genre. *Journalism.* doi: https://doi.org/10.1177/1464884918793933

Höijer, B. (2004). The discourse of global compassion: The audience and media reporting of global suffering. *Media, Culture & Society,* 26(4), 513–531. doi: https://doi.org/10.1177/0163443704044215

Karpf, A. (1988). *Doctoring the media: The reporting of health and medicine.* London: Routledge.

Kilgo, D. K., Lough, K. & Riedl, M. J. (2017). Emotional appeals and news values as factors of shareworthiness in Ice Bucket Challenge coverage. *Digital Journalism*, 811–817 (Advance online publication). doi: https://doi.org/10.1080/21670811.2017.1387501

Klawiter, M. (2004). Breast cancer in two regimes: The impact of social movements on illness experience. *Sociology of Health & Illness,* 26(6), 845–874. doi: https://doi.org/10.1111/j.0141-9889.2004.00421.x

Klinger, U. & Svensson, J. (2018). What media logics can tell us about the internet? In J. Hunsinger, L. Klastrup & M. M. Allen (Eds.), *Second international handbook of internet research* (pp. 367–380)*.* Springer, Dordrecht. doi: https://doi.org/10.1007/978-94-024-1202-4_48-1

Langer, J. (1998). *Tabloid television: Popular journalism and the "other news".* London: Routledge.

Larssen, K. & Hornmoen, H. (2013). The literary journalist as fellow human being. *Literary Journalism Studies*, 5(1), 81–96.

Lovejoy, K., Waters, R. D. & Saxton, G. D. (2012). Engaging stakeholders through Twitter: How nonprofit organizations are getting more out of 140 characters or less. *Public Relations Review,* 38(2), 313–318. doi: https://doi.org/10.1016/j.pubrev.2012.01.005

Moeller, S. D. (2002). A hierarchy of innocence: The media's use of children in the telling of international news. *The International Journal of Press/Politics,* 19(3), 36–56. doi: https://doi.org/10.1177/1081180X0200700104

Orgad, S. (2005). *Storytelling online: Talking breast cancer on the Internet.* Peter Lang: New York.

Phil, B., & Stephen, Z. (2004). Social movements in health: An introduction. *Sociology of Health & Illness,* 26(6), 679–694. doi: https://doi.org/10.1111/j.0141-9889.2004.00413.x

Polletta, F., Chen, P. C. B., Gardner, B. G. & Motes, A. (2011). The sociology of storytelling. *Annual Review of Sociology,* 37, 109–130. doi: https://doi.org/10.1146/annurev-soc-081309-150106

Schudson, M. & Andersson, C. (2009). Objectivity, professionalism and truth seeking in journalism. In K. Wahl-Jorgensen & Thomas Hanitzsch (Ed.), *The handbook of journalism studies* (pp. 29–41). NY: Routledge.

Seale, C. (2002). *Media and Health*. London: SAGE.

Shuman, A. (2005). *Other people's stories: Entitlement claims and the critique of empathy.* Urbana & Chicago: University of Illinois Press.

Thorbjørnsrud, K. & Ytreberg, E. (2020). A Human Interest Economy: The Strategic Value of Turning Ordinary People into Exemplars in the News Media. *Journalism Studies* 21(8), 1093–1108. doi: 10.1080/1461670X.2020.1720520

Tilly, C. (2008) [2006]. *Why? What happens when people give reasons… and why*. Princeton: Princeton University Press.

Vromen, A. (2017). *Digital citizenship and political engagement: The challenge from online campaigning and advocacy organisations*. Springer.

Wahl-Jorgensen, K. (2016). Emotion and journalism. In T. Witschge, C. W. Anderson, D. Domingo & A. Hermida (Eds.), *The SAGE handbook of digital journalism* (pp. 128–143)*.* Los Angeles: SAGE.