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- Jakubowicz, K. (2013). *Nová ekologie médií*. Zlín: Verbum.
- Jenkins, H. (2006). *Convergence culture: Where old and new media collide*. London, New York: New York University Press.
- Lindgren, M. (2021). Intimacy and emotions in podcast journalism: A study of award-winning Australian and British podcasts. *Journalism Practice*, 1–16.
- McHugh, S. (2016). How podcasting is changing the audio storytelling genre. *The Radio Journal: International Studies in Broadcast and Audio Media*, 14(1), 65–82.
- Newman, N., & Gallo, N. (2019). *News Podcasts and the Opportunities for Publishers*. Oxford: Reuters Institute for the Study of Journalism.

HEALTH AND ILLNESS IN DIGITAL PARTICIPATORY CULTURES

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Vicari, S. (2021). *Digital Media and Participatory Cultures of Health and Illness*. Routledge.

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Throughout what some people now call "covid years", the press media in the Western world somehow felt obliged to present the public with daily numbers of new covid-19 infections, deaths, and eventually, recoveries and vaccine applications. This trend of providing information on a single topic practically non-stop was evident particularly at the beginning of the worldwide pandemic. However, it was not only the press that seemed obsessed with data and personal stories of the sufferers or survivors. It was also the general Western society public who demanded and then devoured news through both traditional and new media and participated in campaigns including mask or anti-mask-wearing¹, vaccine communication and "anti-vax" movements, and other forms of active and passive participation while dealing with the worldwide pandemic. It is precisely the time of the

1 One example is the "How to Significantly Slow Coronavirus? #Masks4All" video by the Czech content creator (Petr Ludwig / Konec procrastinace [CZE], 2020), which as of January 23, 2023, has over 5.7 million views on YouTube and which has been shared and commented internationally. The latter saying, "I protect you, you protect me," and its alternations (e.g., "I" being replaced by "my mask" and "you" by "your mask") comes from this video that has been critically acclaimed by scientists and other professionals, particularly in the first months of the covid-19 pandemic.

first year of covid-19's public existence Vicari begins her book "Digital Media and Participatory Cultures of Health and Illness" with. Even though the copyright stands for 2022, it was first published by Routledge by the end of December 2021 amid the above-mentioned global pandemic². And it might have been precisely the pandemic itself that brought more attention to the public participation in health communication, as the main topics in public discussion before this event usually covered other themes. For instance, in case of Spain, those were social issues, the government, politics in general, or immigration issues (Campos-Domínguez & Calvo, 2016) rather than widely spread diseases. I would argue that those could apply to other European countries as well. If health was discussed, it had been usually targeted at a specific group – for instance, the elderly.

It is then primarily natural that Vicari starts her book with such a current and worldwide event that had an incredible impact on the whole of Western society and the overall participatory culture of health and illness, particularly in the digital world, since remote communication was mainly the only option left: Millions of people had to isolate or quarantine due to either their illness or due to policies that took into effect by local governments.

In her introductory chapter, Vicari showcases five "snapshots" of social media content concerning the novel coronavirus from regular social media users

and the general public. These snapshots follow the evolution of their thinking about the pandemic: from the unknown "Wuhan disease" that spread back in 2019 to "super-spreaders", "long-covid" stories, data collection concerns, and eventually, "blue hearts vs. the yellow army" – blue hearts symbolizing the trust in science, while yellow smiley faces were perceived as a symbol of people who were anti-vax/anti-lockdown. The author, however, does not fully dive into details or the context of why she chose even to mention these snapshots. Thus, the end of the introductory chapter seems open for the reader to assume that more space will be given to in-depth research of these snapshots and the overall topic. But this is not the case. The author probably wanted to provide a more contemporary look at specific examples of online participatory culture concerning health. Nevertheless, how it is connected to the rest of the book is unclear and seems to have only attention-grabbing function.

In fact, the book deals with both theoretical and practical implications of the public participating in the communication of mainly rare diseases particularly on social media but also through technology, and the function of the connected patient organizations to these diseases. The author separated the book into three parts: (1) Theoretical Foundations, (2) Digitised and Networked Health, and (3) Platforms. Each of them includes two stand-alone chapters. This gives the book enough structure, and the parts have a logical order.

2 The World Health Organization (World Health Organization, 2020) declared the spread of covid-19 a pandemic on March 11, 2020; however, the first cases appeared in the Chinese city of Wuhan in November 2019.

The first part dives into fundamental theories on participatory cultures in the digital environment, arising from citizen journalism and the case of Indy-media (p. 16) and the first digital participatory platforms such as Wikipedia and the term "produser" (p. 20-21). The author explains the history of the term and its connection to today's world as "the twenty-first century normalized participatory models of content production where traditional role and power boundaries became increasingly fuzzy" (p. 19). *Produser*, in this sense, is everyone who posts anything on the Internet, particularly on social media, and thus, becomes both producer of the content and its user – or consumer.

Vicari then moves on to the emergence of social media, their description, and the way they operate. Here, she asks a crucial question on whether "social media platforms [can] be considered neutral? To what extent are these platforms independent of economic and political forces?" (p. 20). Crucial – because of the business models these platforms work with. In her work, Vicari works around Apple or Google, but together with them also other major technological players offer paid functions and content which anyone can purchase. And as any company – these technological firms aim to gain profit. Furthermore, the political independence decreases with the amount of political regulation of the platforms and the involvement of politicians in the basic functioning of these companies, as well

as involvement of these politicians in using the platforms and the tools provided for their own campaigns.

Vicari also focuses on activism and health advocacy from a historical perspective and looks at how they currently operate. In connection to that and through the work of Brown and Zavestoski (2004), the author highlights "scientization" of mostly political approaches to how information is presented to the public (p. 39). Here, Vicari makes an exception and goes back to the covid-19 pandemic, as she predicts that the role of scientific information in policymaking in different countries will be fully discovered in the coming years. She demonstrates her thoughts on the example of "a scientific advisor" being present at daily political press conferences in the U.K. during the pandemic. She suggests that "[scientization] often constitutes a veiled attempt to conceal the politicization of health policy making" (ibid.). While this is an important finding, the author could have dived into more reasons for scientists or physicians being present at these conferences, such as playing an essential role in fighting fake news about covid-19 that spread massively on the Internet³. Those professionals who decide to include themselves in such campaigns do so usually credibly due to their professional and – mostly – apolitical background. They also must hold onto the ethical standards set by the professional associations they are part of⁴, which supports the idea of a trustworthy professional even more.

3 There are thousands of research papers on fake news during covid-19 pandemic only on Google Scholar.

4 For example – in the Czech Republic, every physician must be a member of the Czech Medical Chamber.

If we, in this sense, look at politicians' actions from the ethical perspective, they usually do not have to deal with such ethical concerns to a great extent apart from their own parties' regulations, national laws, and personal moral beliefs. They can also be burdened with political affairs. Thus, this whole image might lead to the decrease of public's trustworthiness in politicians' way of communication of health topics towards the public.

Moving on, Vicari gives much space to patient health advocacy movements – mainly because of her previous research on rare disease communication. According to her, supporting groups and distinctive "patient advocacy organizations" (p. 40) serve not only as a space for "*collective illness identities*" but, most importantly, as "*partners in decision-making*" who are recognized for their expertise in specific health issues or illnesses, often offering personal stories that "allow others to comment on and offer alternative interpretations based on their own life stories" (p. 45). In their essence, patient advocacy organizations are the definition of participatory culture of health and illness because they connect the patients and their families to institutions and the public. By doing so, they give them their voice mediated not through the traditional media or state institutions but through their unique platforms (websites, blogs, social media accounts).

However, and in connection with this, Vicari discusses some potential issues in so-called "*lay expertise*". This phrase means non-scientific knowledge from people with other rich sources of

knowledge than the scientific ones – such as them or their family member being ill (as part of an "experiential knowledge" commonly used in Vicari's work). These concerns come from the fact that highly scientific information, e.g., on "*genetic knowledge*", can be spread to the general public through non-professionals; and from the discussion on whether this public should be part of a broader conversation on such topics or if it does not raise ethical concerns (p. 59), as Kerr et al. have already mentioned in their 1998 work (1998, p. 41). However, Vicari argues that, for instance, in the case of rare diseases, the demand for such knowledge and participation is more than present due to "the general lack of information on rare diseases" (p. 51) – and, I would add – due to the persisting lack of interest from official institutions. Thus, rare disease patient organizations and movements are vital in health policymaking. I would argue that Vicari could break down the ethical concerns to a greater extent, particularly the topic of the spreading of misinformation. Even though people with experiential knowledge might be well-informed on their own or their significant others' health issues, their lack of professional or highly scientific background might lead to misinterpretation of data, the spread of fake news, and misinformation of other patients who may trust these "lay experts."

Nevertheless, the readers learn from this book that to enhance the connection between professional knowledge and lay expertise, organizations (in this case, rare disease patient organizations) do use various digital tools to enhance not

only one-way and two-way processes of information exchange but also "crowd-sourced processes of health knowledge sharing, exchange, and co-production" which then "provide personalized routes to health public engagement" (p. 94). They can do it through what we call "telemedicine", "epatient", "eHealth", or "mHealth", - or simply digital tools in patient-physician relations - which can "enhance the delivery of health services from providers to consumers, ... shortening patient-physician physical distances, enhancing public campaigning for behavioural change and strengthening health surveillance strategies" (p. 70) - and, from my perspective, they can be a powerful tool in immediate spreading of professional advice to groups endangered by consuming disinformation on the Internet, such as teenagers or the elderly.

Nevertheless, such tools can also work through various *platforms*, which Vicari dedicates the final part of the book to. By the term, the author means various digital participatory platforms for the public - social media or mobile or Internet applications/PC programmes. Looking first at mainstream social media, specifically Twitter, Vicari presents her earlier work on posts mentioning BRCA rare disease on this platform - especially when the movie celebrity Angelina Jolie announced her being the BRCA1 gene carrier and, with it, her decision to undergo a series of surgeries which immediately became a controversial topic in the media. Around the same time, there was another controversy over Myriad Genetics' human gene patents which "increased the price of BRCA

genetic testing, reducing its accessibility" (p.104) and the connection between Angelina Jolie raising awareness and the price of the testing was much discussed on Twitter, but the question was how the specific patients could get to this information to even get the chance to participate on a story set by a celebrity. The author presents the results of her Twitter posts studies which took place a month before, during, and after Angelina Jolie's op-eds in both 2013 and 2015. On these, Vicari explains two dimensions that she identifies as "extremely relevant to digital participatory cultures" - curation and framing practices. With curation, the author identifies that the platform - again, Twitter in this case - uses algorithms that already act as curators of the content, but at the same time, the users themselves can curate the content by many functionalities of the platform, such as tags or retweets (p. 101-102). These practices can influence the dynamics of topics discussed on a particular platform both short- and long-term. The discourse can also be influenced by framing - using hashtags to frame topics - but in her work on BRCA tweets, Vicari found that the role of framing tends to be relatively short-term. Overall, the practices mentioned above do immediately affect whether the topic is widely discussed among the public, as these practices use tools that are easy to understand and can get to a wide range of people who follow a specific topic.

Another two dimensions - storytelling and epistemic dynamics are discussed in the presentation of the author's further research on BRCA

tweets from 2017. Here, I would highlight mainly the storytelling part, which is one of the most relevant to the whole digital participatory culture in the context of this book and the most exciting part to this point. When Vicari navigates through the relationship between the public sphere and social media, she pays attention to the fact that "people do not necessarily engage in campaigns or activists' debates on social media and elsewhere because of their political party affiliation or as members of a pressure group (e.g., Greenpeace); they do so because the campaigns or debates resonate to their life story" (p. 27). And for that to happen, storytelling is essential. It can demonstrate even complicated issues through personal experience, and personal storytelling narratives can be helpful in many areas of human interest – from translating science or hard news to the public (as mentioned by, e.g., Avraamidou & Osborne, 2009; or Ekström, 2000), to active including of the public in creating or communicating a problem. A personal story might allow the public to draw attention to a problem, even without the "hard" data. In this sense, storytelling is a part of the infotainment culture, which we can also see in influencers' content on social media platforms. Here, I see an interesting twist as Vicari mentions that a third person published most of the stories shared on Twitter, and not a first person. For example, Pachucki et al. found that "first-person compared to third-person storytellers significantly increase engagement on social media" (2022, p. 1703). Even though these researchers conducted their research around

storytelling in destination marketing, I would argue that their conclusion could also be applied to current health communication. It is then a question to what extent does the fact that Vicari focuses mostly on rare diseases play affect this, as the patient organizations often work as a mediator.

While reading through the part on storytelling, however, I questioned the principal decision to include Twitter as a primary platform in Vicari's research. In the European environment, Twitter is not usually a platform for storytelling but rather for "hard news" – for instance, in Norway (Kalsnes & Larsson, 2018) but also in Czechia. I acknowledge Vicari's mentions of other scholars claiming that Twitter is a storytelling platform (Papacharissi, 2016; Rogers, 2019). I argue that this highly depends on the geographical placement of the discussed culture. Here, the culture of Anglo-Saxon countries is only a part of Western culture in general, and in its essence, it is very different from the continental European culture. It is interesting that later in this part of the book, Vicari mentions "storytelling units using external sources" (p. 122) in connection to Twitter – these could be links to websites and other social media. This to me indicates that Twitter does not serve as a primary social medium to share the primary news story but rather as a tool in a communication mix for spreading it to as many people as possible. Moreover, in the introduction to the "storytelling" part of the chapter, the author says that "this research is providing in-depth explorations of the development of non-traditional forms of storytelling, where

visual content plays a key role" (p. 112). While I do agree with this statement, I am not sure whether a social medium site like Twitter applies to it, as at present and even back between 2017 and 2021, the period in which apparently Vicari's book was mainly written, we could find other platforms that rely primarily on visuality, such as Instagram, Snapchat or Tiktok. Moreover, Twitter is widely perceived as a micro-blogging site with various limitations, such as the number of characters the users can use, which now stands at 280. It was even half of that before November 2017 – and those characters reduce when the user adds any medium – a picture, an emoji, or similar. Altogether, Twitter has a difficult position in terms of storytelling, as it does not really provide the suitable environment for such activities.

Just before the conclusion, Vicari also mentions other platforms different from social media that can be used in participatory cultures which we could connect to eHealth/mHealth technologies. She distinguishes four platforms according to their purpose and provides an example for each of them. These are as follows: *Fitbit* (tracking platform), *23andme* (self-diagnosis platform), *ParentsLikeMe – PLM* (patient experience exchange platform), and *CareOpinion* (feedback platform). Through these examples, she provides eight propositions on digital health platforms – from my point of view, the most important ones here being commodification of the collected data, digital platforms as data-veillance systems, and data provided to users as a means for resistance. However, Vicari does not further develop

these propositions but only summarizes her findings and the purpose of this section is, thus, unclear.

This development of ideas or any criticism is not present even in conclusion, giving the whole book a more positivist approach by stating facts and presenting her previous or other researchers' work (e.g., with Cappai in Vicari & Cappai, 2016) rather than using a strong topic like this to build new and unique arguments and discover emerging issues concerning ethics, for example. I particularly awaited a stand-alone chapter dedicated to ethical issues because, as mentioned above, ethics are an essential part of health communication in general – this applies to professional communication by medical practitioners but also to political ethics and moral values when communicating false or unrealistic hopes for the patients (see, e.g., Moravec, 2020). I would also welcome a part where Vicari would talk about disseminating fake news in digital space available to anyone particularly during the covid-19 pandemic. I would appreciate it if, for instance, Facebook groups or pages focusing on an alternative approach to covid-19 medication or prevention would be at least mentioned in this book. It is also precisely the covid-19 pandemic that, although present in this work at the beginning and boosting up the introduction part, is very much ignored later (with one exception). Generally, the focus is more on rare diseases rather than illnesses, pandemics, and other health issues concerning the whole society. While I understand the focus on rare diseases and dedicated patient organizations as they provide excellent

and specific examples of participatory culture of health and illness, the book would benefit from expanding the introduction about covid-19 to another stand-alone fourth part of the book; or at least a single chapter.

On the other hand, Vicari presents a very structured work backed by an impressive amount of research. Despite my criticism, this book provides an essential insight into the participatory culture of health and illness, not just because of the covid-19 pandemic. The Western culture has been turning towards a highly profound health-based approach in all aspects of life. That is, doing more physical activities, self-tracking various health indicators, caring for mental well-being, or raising awareness about the connection between health and environmental threats – for instance, through vegetarianism and veganism or even through participatory culture, such as sharing a personal story to raise awareness about health threat; or just to set an example to others when sharing food diaries or exercise routines. I believe some of the findings in this book could be applied to other pandemics as well. In my research I focus on obesity pandemic and obesity communication in the media, and I do see a prospect for comparison of the participation of people struggling with overweight in body-positivity movement on Instagram with rare diseases communication on Twitter. Thus, this book serves as a solid ground for future research development from which other scholars can benefit.

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REFERENCES

- Avraamidou, L., & Osborne, J. (2009). The Role of Narrative in Communicating Science. *International Journal of Science Education*, 31(12), 1683–1707. <https://doi.org/10.1080/09500690802380695>
- Brown, P., & Zavestoski, S. (2004). Social movements in health: An introduction. *Sociology of Health & Illness*, 26(6), 679–694. <https://doi.org/10.1111/j.0141-9889.2004.00413.x>
- Campos-Domínguez, E., & Calvo, D. (2016). Participation and topics of discussion of Spaniards in the digital public sphere. *Communication & Society*, 219–232. <https://doi.org/10.15581/003.29.35816>
- Ekström, M. (2000). Information, storytelling and attractions: TV journalism in three modes of communication. *Media, Culture & Society*, 22(4), 465–492. <https://doi.org/10.1177/016344300022004006>
- Kalsnes, B., & Larsson, A. O. (2018). Understanding News Sharing Across Social Media. *Journalism Studies*,