Why people sometimes consult Facebook groups rather than their doctors. Devils in the detail, methods to the madness

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Health-related Facebook groups is a social media phenomenon that in recent years has become popular among Danish individuals who struggle long-term with a diversity of health-related issues. These groups typically organize themselves around *specific health problems*, such as migraine or gluten intolerance, or around *specific approaches* that users employ for battling different health problems, such as medical marijuana or specific lifestyle changes. For these groups, it is a common trait that they assemble large numbers of ordinary people who struggle with health-related problems that appear similar in character, and that they extend everyday individuals' opportunities for qualifying how to better deal with their troublesome health through discussion with others who find themselves in a similar situation.

In this dissertation, I present a media ethnographic research project that inquires the symbolic meanings of these health-related Facebook groups and the use practices that revolve around them.

The dissertation is organized around the following three research questions. Two of these are empirical in character, one has a methodological scope:

- What is the raison d'être of health-related Facebook groups, and how can we understand their striking popularity?
- How do media users employ these Facebook groups in their health-related sense-making, when they face the challenge of figuring out what is wrong with their health and what they themselves can do about it?
- How can we as researchers study people's intimate and normatively contested social media use without stigmatizing them or violating their privacy?

Empirically, the responses provided to these questions in this dissertation draw on extensive *flow-oriented* (Markham and Gammelby 2017) fieldwork that is primarily conducted between 2013 and 2019. This fieldwork comprises 48 different health-related Facebook groups (41 Danish language groups and 7 English language groups). Also, it comprises curious interview-based collaborative analytical exploration with eight Danish speaking media users, who all happen to use or have been using health-related Facebook groups over a longer period of time in relation to a health-related problem of their own. Furthermore, the fieldwork has an auto-ethnographic dimension, as I have myself been an ordinary user of several health-related Facebook groups since 2011, and as I have proactively been using my default embeddedness in my field to explore it further, for example through different kinds of situational and auto-phenomenological mapping.

Epistemologically, the research project is conducted within a symbolic interactionist framework. In practice, this means that the analysis provided deliberately seeks to bring forth how media users themselves assign meaning to social media as well as how they understand their own practices around and reasons for interacting with health-related Facebook groups.

This is a portfolio-based dissertation. It consists of four separate research publications that can be read independently. These are integrated in a longer dissertation text, which presents the coherent argument of the dissertation. Two of these publications are written in collaboration with co-authors.

The dissertation is divided into three sections:

Section 1 (chapter 1-3) comprises an introduction to my research project and my analytically constituted object of study. Chapter 1 consists of a number of ethnographic vignettes that are interwoven with theoretical reflections and contextualizing perspectives on my empirical phenomenon of interest. Chapter 2 is a more classical academic presentation of my research project and its methodological approach. Chapter 3 presents how I position my

research project in relation to a range of research traditions and disciplines that my research, on the one hand, ties into, on the other hand, bridges knowledge gaps in-between by virtue of contributing with non media-centred (Couldry 2010) media and communication research-based insights into what we as everyday individuals *do* with the digital media that surround us.

Section 2 (chapter 4-9) is a deep-dive into my methodology and the methods I have developed as part of my research project. Chapter 4 and 5 each features a separate research publication. Publication 1, "Moving through digital flows: An epistemological and practical approach" (Markham and Gammelby 2017) is a book chapter published in *The Sage Handbook of Qualitative Data Collection* (Flick 2017). It introduces a *flow-oriented* methodology for doing social research in digital contexts. Publication 2, "Agential hysterias: A practice approach to embodiment on social media" (Tiidenberg, Gammelby, and Olsen 2020), is a book chapter published in the anthology, *Mediated Interfaces: The Body on Social Media* (Warfield, Cambre, and Abidin 2020). It is an evocative palimpsest on normatively contested digitally mediated embodiment.

In chapter 6, I elaborate on my flow-oriented methodology and methods. This chapter stresses the epistemological importance of looking beyond the vast amounts of user-generated content that immediately leaps out at us on social media, when our analytical objective is to understand the interplay between media and culture. Also, this chapter presents how I have, through flow-oriented research practice and by employing a variety of grounded theory-inspired mapping techniques, inductively approached my (auto)ethnographic field, iteratively challenged my analytical conceptualizations, and critically related to my own research position. Chapter 7 and 9 provide a more hands-on presentation of my ethnographic engagement with health-related Facebook groups and my one-on-one engagement with media users in my field, while chapter 8 elaborates my reasoning and strategies for navigating certain ethical dilemmas that have emerged in my research process.

Section 3 (chapter 10-15) of the dissertation features my research findings. These findings are summarized below.

Research findings

Chapter 10 and 11 each presents a publication manuscript that features empirical analysis of health-related Facebook groups. Publication 3, "Mapping the 'wicked' situational aspects of health-related Facebook-groups" (Gammelby, unpublished manuscript) is an article manuscript devised in relation to the conference, *4S 2017* (Society for Social Studies of Science's annual meeting). It analyzes how health-related Facebook groups excel in rendering five situational aspects of life with long-term health problems increasingly publicly visible, namely 1) that health problems are not merely medical problems, 2) that a particular health problem may very well express itself rather differently in different human bodies, 3) which medical services are part of the public healthcare repertoire and under which circumstances these may become available, 4) which lived-experience shortcomings and inconveniences patients may associate with these services, and 5) a range of alternatives or supplements to authoritative healthcare knowledge and treatment that mundane individuals have identified on their respective health-related sense-making trajectories, alternatives and supplements that from an embodied perspective suggest that public healthcare may not always provide the only or the better pragmatic solutions for addressing everyday health problems. The intensified visibility of these five situational aspects contributes to a broader situational overview that media users, who face health problems that are experienced as "wicked" (Rittel and Webber 1973) in character, find particularly useful.

Publication 4, "Aren't Facebook groups merely echo-chambers spreading fake-news online?" (Gammelby, unpublished manuscript) is a conference paper devised in relation to the media and communication conference *NordMedia 2017*. It highlights through ethnographic analysis that there may often be a significant discrepancy between how media users discuss health-related knowledge in Facebook groups, and how users respectively relate to the truth value of the health-related information shared within these groups. More specifically, it emerges in my fieldwork that users may regularly refrain from voicing explicit critique in health-

related Facebook groups, when they do not agree with the other users. This partly relates to users generally accepting that all personal perspectives have a value in their own right, and that these are but situated (not universally valid) perspectives. Partly, this relates to an interest among users in not undermining health-related Facebook groups as venues for bringing one's personal health-related considerations to the table without feeling exposed or antagonized. These visibility biases highlight that we cannot by default anticipate that the user-generated content in health-related Facebook groups necessarily reflects the respective media users' health-related convictions. Methodologically, this complicates the task of social researchers relying on user-generated social media content as the only data for understanding how digital media such as health-related Facebook groups in practice affect media users' stances on health-related matters.

In chapter 12, I present eight situational circumstances that I in my fieldwork regularly observe invites media users to seek out health-related Facebook groups or even create new groups in relation to health-related topics of interest. These circumstances strongly contribute to the raison d'être of health-related Facebook groups, as they, when they apply in everyday life, contribute to actualizing (and socially reifying) the five situational aspects that these groups excel in rendering visible (cf. publication 3) as relevant communicative affordances (Hutchby 2014) of these groups. These circumstances relate to 1) the duration of the health-issue, 2) associated way-of-life obstructions, 3) diagnostic uncertainty, 4) antagonism with healthcare around diagnosing, 5) treatment issues, 6) antagonisms around treatment, 7) the potentials of dietary changes, and 8) individual risk assessment, partly with regard to the health-issue itself, partly with regard to the burdens of exposing oneself to knowledge perspectives that are not vetted by authorized healthcare. These findings suggest that the raison d'être of health-related Facebook groups widely resides in the *unresolved* health problems that digital media users face in their everyday lives (that is, *beyond* media as such). At the same time, the popularity of health-related Facebook groups and the fact that users have over time managed to collaboratively reify the five situational aspects that health-related Facebook-groups render visible into reliable functionalities of these groups suggest that certain everyday experiences of the situational circumstances mentioned above are relatively common in relation to health-related problems in society.

In chapter 13, I present a concept that has emerged in my inductive ethnographic research, namely the concept of *body hacking*. Body hacking refers to the curious sense-making practice, that many media users in my field engage in, when they consult digital media, such as health-related Facebook groups, but also a variety of quantified self/self-tracking technologies for example, on their endeavors to better comprehend how their bodies react under specific circumstances and what they *themselves* can do better to optimize their health. In brief, body hacking is about self-directedly figuring out the invisible "code" – may this be biological or environmental – that determines one's bodily performance and well-being, ultimately with regard to empowering oneself to reconfigure this code and live the best life possible, despite facing health-related challenges. Similar to for example computer hacking, bio hacking, or 'life hacking', body hacking is widely a trial and error-based practice that revolves around iteratively modifying certain factors in unconventional ways and monitoring the result in a kind of feedback loop. As such, body hacking is not a digital media practice. However, digital media strongly facilitate body hacking, because they advance media users' opportunities for engaging in curious bodily introspection and for juxtaposing their personal sense-making with the sense-making of "savvy" other digital media users. On the basis of my research, it is not possible to determine whether health-related Facebook-groups as such lead to more body hacking or more medically controversial forms of body hacking. That said, health-related Facebook groups increase the visibility of body hacking across time and space, which per se contributes to normalizing the act of adopting the role as empowered health-related decision-maker who navigates between different forms of expertise on the domain of health, a role that is highly characteristic of body hacking as a mundane, health-related sense-making practice.

In chapter 14, I summarize my methodological points on how, not to say *if* at all, it is fair and possible to study how people discuss their personal health-issues online, considering the fact that it is often neither practically possible, nor ethically justifiable to try inform users or retrieve informed consent. Here, the methodological outcome of my research is that it is of relatively little importance to media users' experiences and their conceptual consents to have their personal data become subject to research, whether this data is retrievable from

health-related Facebook groups that are publicly accessible or protected by certain privacy settings. Instead, it is of utmost importance to ensure that the meanings users themselves assign to their data is maintained when I interpret their data and present it in an academic context. In other words, my empirical research highlights the ethical importance of ensuring that the media users' whose digital media practices I study are in practice represented in my research in ways where they may be able to recognize themselves and their digital media use in my analytical account.

In order to ensure such contextual integrity, the methodological frameworks and strategies I have presented in section 2 of this dissertation have been particularly useful, because they invite digital researchers to interact iteratively with their field and thus sensitize them to media users' situated meanings while they encourage researchers to relate with a certain degree of irreverence to his/her own preliminary understandings and continuously negotiate his/her analytical conceptualizations of the field. In particular when we study digital media phenomena that are normatively contested in society, this appears methodologically critical, because it is both widely possible and tempting to generate quite detailed analytical narratives about distant others on the basis of their digital footprints, and because vast experiential and conceptual distance between researcher and media users at the same time involve a significant risk of the researcher inadvertently taking media users' data into account for knowledge claims that may likely seem valid from a detached researcher point of view, but in fact are experienced as stigmatizing or as a misrepresentation of the field from an empirical point of view. Thus, my research highlights a relatively overlooked ethical problem in digital research. The potentially vast distance between researcher and media users in digital contexts, however, also comprises a challenge to the analytical quality in digital sociological research – in particular in an era where the enthusiasm for "data-driven" approaches is growing, and where it is regularly expressed as a privileged pathway to meaning to "let the data speak for itself" – because the default distance that typically applies in digital research, demands the researcher to take active measures to ensure the grounding of their analysis and sensitize himself/herself to what the *field* wants us to know.