

THE LANGUAGE OF ILLNESS
AND DEATH ON SOCIAL
MEDIA

Sharing Death Online

Series Editors

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Humans face and deal with death and loss through media and technologies at hand. In contemporary culture, online media is perhaps the most important arena for the (re-) interpretations, (re-)mediations, and performances of traditions, practices, and beliefs related to death and dying. While some of these traditions are indeed new and digitally born, others are revitalizations of older death-related practices.

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THE LANGUAGE OF ILLNESS AND DEATH ON SOCIAL MEDIA

An Affective Approach

BY

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The book mainly consists of new work, but small, theoretical, and analytical sections have been amended from passages in the journal article “Interjections, phonetics, and the

body” (Hougaard, 2018), and the book *Networked Cancer* (Stage, 2017).

Carsten Stage

London, June 2018

Tina Thode Hougaard

Aarhus, June 2018

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CHAPTER 1

INTRODUCTION

Social media is now an ordinary, integrated, and natural part of everyday life for many people all over the world. The internet and social media have, in the words of John Durham Peters, become “elemental” (Peters, 2015), which means that we should approach this technology “as a means of existence, in some ways close to water, air, earth, fire, and ether in its basic shaping of environments” (Peters, 2015, p. 49). Yet, because it is so “ordinary” and “elemental,” social media is also becoming increasingly engrained in the extraordinary dimensions of existence and a fundamental part of the changing nature of life, in which unexpected events can suddenly transport us from the ordinary to the extraordinary. This implies that, on social media, we can observe individuals occasionally turned into “existers” when faced with biographical disruptions linked to events such as illness and death (Lagerkvist, 2016). Social media is thus being increasingly used to deal with life’s crises – yet it can also play a role in creating the very same crises. According to Amanda

Lagerkvist, social media is “existential media” in a double sense: it can contribute to forming existential crises (e.g., through processes of cyber bullying or digital assaults and conflicts) and help to manage and deal with existential crises (e.g., through various forms of digital communication, such as support groups and online forums) at the same time.

In this book, we take a particular interest in existential and affective publics that arise on Facebook groups that deal with the diagnoses, treatment, and terminal consequences of cancer among children. More specifically, we focus on the language created and used to shape these publics in relation to personal stories of illness, dying, and mourning. “Language” in this book does not refer to the abstract grammar of or system behind digital media (Manovich, 2001) but rather to the actual utterances, signs, and expressions that people use during interaction on social media. Our key objective is thus to develop an analytical framework to understand the role of what we will call “affective language” – for example, emojis and interjections and other forms of expressive interactive writing – in these publics and to understand how this language can be used to explore shared affective processes of digital affect cultures (Döveling, Harju, & Sommer, 2018) on social media groups that concern events that both profoundly disturb but also necessarily become part of everyday life practices for the involved families and followers. In doing this, our analyses draw on both established and recent research on social and existential media, affect, and language with relevance for social media communication about illness and death.

During crises, users of social media (with varying degrees of intention) produce various forms of linguistic signs and expressions, images, and semiotic actions and thus “entextualise” processes of illness and death in new ways (Giaxoglou,

2015a); however, it is becoming somewhat unfashionable to study this type of material due to media and cultural studies' attempt to avoid framing media as mere channels for content and textual circulation. Through the work of seminal figures such as Innis, McLuhan, Kittler, Carey, and Meyrowitz, we have been taught that media do not simply transport meaning or semiotic content but also fundamentally change and condition social spaces, relations, and hierarchies of knowledge, which implies that we should "take media less as texts to be analysed [...] than as the historical constituents of civilization or even of being itself" (Peters, 2015, p. 18). For this reason, language and written texts have become somewhat outdated objects of study due to textual research's earlier tendency to neglect the cultural changes brought about by the affordances of media. And we agree: it is far too simplistic to understand social media platforms as textual highways. They are complex social, relational, affective, and economic platforms, which condition, mold and impinge their logic on cultural practices and being in a variety of ways (Hepp, 2012; Hjarvard, 2008). However, importantly, they are also habitats for language use – verbal and visual actions. The exchange of writings and images is still a significant part of social media and a key reason for engaging with them as a user – perhaps not only for the semiotic content or meaning of these exchanges (and certainly not only for the joy of reading enclosed products of writing) but also for the exchange of something more affective, relational, or social in character.

A key interest of this book is how research can avoid treating media as mere carriers of meaning – for example, by stressing and understanding their elemental and existential importance – yet actually be able to investigate the language that "takes place" on social media. With this goal in mind,

we wish to adopt an explorative approach to social media language that begins with the following questions:

- How can language be approached in ways that foreground the bodily relationality and affectivity of communication and social media?
- What can the use of language teach us about the existential, relational, social, and affective processes taking place in cancer-related publics and commemorative sites on social media?

In asking these questions, this book deals with social media as an important affective platform for communication about processes of illness, death, and mourning. Importantly, the attempt to understand the language and interaction of illness and mourning on social media – less as semiotic meaning and more as contributing to forms of being together, confirming relations, and connecting bodies – finds good backing in a range of both recent and classical theories of language that do not place meaning at the center (e.g., theories that deal with the phatic communion, indexicality, and interjections). In this sense, the book can also be seen as an attempt to connect these rather established understandings of language to a specific field of research on social media, which concentrates specifically on how illness and death are communicated on these platforms. Besides this, the book also indirectly adds to the increasing interest in developing methodologies and analytical strategies for understanding the role of bodily affects in relation to social media communication (Coleman & Ringrose, 2013; Knudsen & Stage, 2015b; Vannini, 2015).

In the remaining part of this introduction, we will outline the book's methodological and ethical framework. The next three chapters represent the theoretical context and two complementing analytical approaches. Chapter 2 provides an

overview of the existing, key theoretical concepts, which we later draw on in our analysis. The third chapter focuses on particular types of affective language in the book's two case studies (described later), and the fourth chapter offers an analysis of the accumulation and rhythm of this language and what these rhythms of accumulation might teach us about the differences and similarities between the two affective and existential publics being investigated.

1.1. METHOD AND ETHICS

This book focuses on two Danish cases, which are both public and parent-controlled Facebook groups dealing with children cancer: *Commemorative site for Lærke Rønde Timm and Fighting for Magnus (MIV)*. These cases seem to be part of a growing tendency of not only public children's cancer profiles and groups (*The Bradley Lowery Foundation* and *Caring for Kian* are other key examples) but also of a larger group of entrepreneurial cancer blogs and profiles (see Stage, 2017). Of course, we could have selected to study many other types of social media profiles and groups on illness and death (for example, personal or collective blogs or profiles on Facebook, Instagram, Twitter, or other platforms; closed support groups; or intentional or un-intentional RIP pages), but we decided on the two cases mentioned as they are paradigmatic of many similar illness and mourning groups yet also display internal variation (Flyvbjerg, 2010). The groups are similar in having created intense, affective publics, and in having transformed from first focusing on cancer treatment, then on the processes of dying, and finally on creating a forum for commemoration and grief work related to a particular child (Lærke Rønde Timm and Magnus Eid Andersen (nicknamed MIV)).¹ In this sense,

these cases can help us understand larger ongoing cultural transformations in the development of new affective publics of sharing illness and grief on social media – and not least shed light on how language is used in these publics – and to some extent challenge our understanding of language merely as a system for semiotic meaning-making. However, the cases are also dissimilar in terms of their scale of dissemination, which, through an analysis of affective language use, might allow us to tease out some important differences in how affective publics develop in relation to illness and dying on social media.

Our aim with the book is not to schematize a universal theory covering all verbal and multimodal actions in the two cases, but instead to deepen our understanding of the “affective practice” (Wetherell, 2012) of writing – for example, interjections, hesitation dots, and emojis – on social media. In doing so, we wish to propose a way of investigating more or less spontaneous transmissions of reactions and affects by first focusing on the most-used expressions and prominent posts and second on when and how these expressions are (or are not) used over the larger lifespan of the groups and what this can tell us about their affective logics.

The empirical basis of the book is primarily collected digital material (material *from* social media) and secondly material creating knowledge about living a digital life (interviews *about* social media). More specifically, we use (1) social media and multimodal texts from Facebook related to the two cases and (2) supplementary interviews with the bereaved parents (the two mothers). In processing the material, the book will use a mixed-methods design that combines (1) linguistic, narrative, and rhythm analytical approaches (various forms of theory-based analysis) and (2) digital software (Digital Footprints). These methods are combined in order to be able to explore both the specific affective and linguistic

qualities of the cases, including the type of responses they motivate, and to process the often extensive amount of online material. All digital material has been collected and is being stored (and deleted) according to the “General Data Protection Regulation,” and all use of direct citations deriving from the Facebook groups and the interviews have been approved by the people articulating them.

As part of this method, we have combined manual reading and close reading with digital counting. In Lærke’s case, we read all the blog posts and comments (249 posts and 2675 comments), but, in MIV’s case, due to its size (5,224 blog posts and 44,777 comments as counted by the methodological software Digital Footprints), we read all the posts but only comments on selected dates of importance to the overall development of the case. The statistical access to both cases offered by Digital Footprints enabled us to create an overview of the overall patterns of language use in the data, for example, lists of the 100 top words (both total and on selected dates) and lists of posts that generated the most comments and likes, though this of course does not approach the realm of “big data” or “data linguistics.” We rather used these digital counting tools to identify relevant focus points for conducting theoretical readings based on concepts such as affect, indexicality, modality, and rhythm concerning conventionalized language as well as phenomena on the periphery of the linguistics, such as interjections, emojis, hesitation dots, capital writing, and sign redundancy. Unlike other studies on mourning, we thereby insisted on exploring language use in its natural settings opposed to lab settings (Brubaker & Hayes, 2011). We also conducted a brief online interview with the mothers of Lærke and Magnus about their experience of sharing processes of existential struggle and grief in the Facebook group.

The two cases selected as main material for the book raise a range of important ethical questions, which we will continually bear in mind as we present the material. According to the 2002 and 2012 ethical recommendations of the Association of Internet Researchers (AoIR), what is ethically acceptable is highly dependent on the content, platform, and context of the study and “ambiguity, uncertainty, and disagreement are inevitable” (Ess & AoIR ethics working committee, 2002, p. 4; Markham & Buchanan, 2012, p. 4). An important ethical guideline, however, is to “do no harm” (Ess et al., 2002, p. 8), meaning that the research should result in no physical or psychological negative effects. We take this as our point of departure when dealing with the ethical challenges of the material. Following this, the collection of empirical material is based on informed consent by the parents, who were able to withdraw from the project at any time if they wished. All the regular users who commented on the Facebook pages have been anonymized; however, when quotations have been used that can be traced back to a specific person, this use has been approved by the person in question. Furthermore, we offered the parents the chance to read and comment on the book manuscript before it was submitted for publication. In doing so, we hoped to ensure that the parents were not hurt by our writing and, just as important, that the parents actually felt empowered and understood by our analysis and text.

NOTE

1. Throughout this book, the two children will be referred to as Lærke and MIV.