

## **Prolonged Grief Disorder**

*An Implementation Gone Awry and a Researcher Going Gonzo*

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*Published in:*  
International Journal of Qualitative Methods

*DOI (link to publication from Publisher):*  
[10.1177/16094069211020176](https://doi.org/10.1177/16094069211020176)

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*Publication date:*  
2021

*Document Version*  
Publisher's PDF, also known as Version of record

[Link to publication from Aalborg University](#)

*Citation for published version (APA):*  
Lund, P. C. (2021). Prolonged Grief Disorder: An Implementation Gone Awry and a Researcher Going Gonzo. *International Journal of Qualitative Methods*, 20. <https://doi.org/10.1177/16094069211020176>

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# Prolonged Grief Disorder

## An Implementation Gone Awry and a Researcher Going Gonzo

*International Journal of Qualitative Methods*  
Volume 20: 1–13  
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DOI: 10.1177/16094069211020176  
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Peter Clement Lund<sup>1</sup>

### Abstract

In this article I discuss the muddled implementation of Prolonged Grief Disorder in a Danish context. I do this by drawing on my fieldwork, which has been ongoing during the last couple of years. I begin by describing how my initial research design suffered a breakdown that mirrored the breakdown in the implementation of the Prolonged Grief Disorder diagnoses. This breakdown became defining for my work and through the application of what I call gonzo sociology I was able to critically engage in the field of grief research in Denmark. I describe what gonzo research is, and then, following this, I tell the story of how I stumbled into the field of grief research in Denmark and the process of realization I went through. The article is thus structured as a narrative that relays both how I came to embrace gonzo research as a form of methodology, but also the story of what my encounters in the field showed me. I do this because I cannot separate the story of how I went about it from what I came to discover—methods, theory and results are intertwined. Gonzo research aims at going into the field and participating, co-creating the discoveries and pushing the boundaries for research, both in its way of doing research and in its way of reporting said research. Thus, the form of the article is alternative and balances between journalistic endeavor, academic research and autoethnography.

### Keywords

methods in qualitative inquiry, ethnography, autoethnography, narrative research, ethnomethodology

### Introduction

In 2017 the research center, *The Culture of Grief*,<sup>1</sup> was established at Aalborg University in Denmark. The goal of the center was to research grief from different perspectives, and hopefully give a tentative outline of the current culture of grief. The motivations for doing it at that point in time, were to be found in the International Classification of Diseases (ICD-11), which would be released in 2018 and fully implemented by 2021 (World Health Organization, 2018). In this manual, a new disorder had arrived, called Prolonged Grief Disorder, which meant there was a specific diagnostic classification dealing with grief. At the research center a Ph.D.-position was established, which aimed at researching the diagnosis' implementation in Denmark from a sociological perspective and that position was given to me. As I began settling into my position, it slowly became clear to me that the diagnosis wasn't here yet and that it had been delayed without any clues as to when it would be implemented. This left me—at the time being—with-out an object or phenomenon to research. My plan had been to see what happened when the diagnosis came, who received it and what it did to and for them, who gave the diagnosis, and

what were their thoughts about it. All of this was thrown to the wind shortly after I was hired. Suddenly, I had no place to gather the data I needed, and I had no informants I could interview about their experiences with the diagnosis. I had suffered a breakdown<sup>2</sup> in my research (Alvesson & Kärreman, 2011). I mulled endlessly over my research and my inability to focus and rethink my project—even considering what I was doing in this job and if I should find something else to do with my life. In what follows, I will try to tell the story of how this changed through what I later came to call a form of gonzo<sup>3</sup> sociology or research (Kumm & Pate, 2018; Sefcovic, 1995; Wozniak, 2014). Thus, this article is not just a methodological discussion and neither a report of my findings, instead, adhering to gonzo research, it is the story of how my research and

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choice of methods came about, told as a narrative. Therefore, the article veers drastically from conventional academic style and writing. I do this attempting to both show how research is often messy, how I went about grasping that messiness, and perhaps taking a small step further in the advancement of “gonzo sociology” as a form of research methodology.

I begin by introducing the instigating elements of my work, how my research broke down, how my research took form as a mystery, and how I partially “solved” this mystery through a gonzo approach and what this entails from an ontological and epistemological perspective. I then begin by telling the story of how I went about my research and in this process came to realize how to do my research, what I was researching, and what was important. This is a narrative driven by my gonzo approach to both doing and reporting my research. I tell the story of certain key moments and incidents in my time as a Ph.D.-student that both made me aware of what was at stake with the implementation of the new diagnosis and how I needed to do my research. I end with a short discussion of my methods and what my research has shown about the process—and lack thereof—of implementing a new diagnosis in a Danish context.

## **Part I—How Nothing Turned Out the Way I Wanted It to and What I Did About It**

### ***Breakdowns and Mystery***

One point that is important for me to get across, is that how my research played out and how I conceptualize it now, came after the fact. I had, in fact, nothing that resembled a clear research design as I began collecting data and doing field work and only had vague ideas of where to look. I realize now, that this way of thinking about qualitative research is, in several ways, a benefit and “mucking about” (Van Den Hoonaard, 2011) is a viable way of approaching research design that may lead to epiphanies. Two things became central for my happenstance form of methodology: The idea of breakdown-driven research (Alvesson & Kärreman, 2011) as a form of abductive<sup>4</sup> reasoning and the concept of “gonzo sociology” (Wozniak, 2014). The idea of research as breakdown-driven is, obviously, meaningful since my research was instigated by a breakdown—one that involved my own design, but more importantly was involved with the implementation of Prolonged Grief Disorder in a Danish context and the fact that this work was in the midst of breaking down as I began researching. As Alvesson and Kärreman (2011, p. 16) point toward, doing qualitative research is about the construction and the resolution of a mystery. Writing meaningful and good social science is akin to writing a good detective story<sup>5</sup>: You discover something mysterious and attempt to resolve it by the end of the text. Now, this might seem closer to fiction than science, but it is important to note that the point here is *not* that you write a fictitious story concerning whatever you feel like. Instead, it is about conveying the given research in a meaningful manner—for me this has two intentions: Writing an article that discloses the points in a style that is pleasing

and exciting, and, more importantly, because my actual research had a sense of this unfolding mystery.

The nature of the phenomenon I was researching is best conveyed through my experiences. Not that my research is to be understood as a neat, linear, packaged story with a beginning, middle and end, but it still had a sense of figuring out what this mystery meant. Writing this form of detective story is not just something that “happens”—it requires skills and academic know-how to find a mystery and tentatively resolve it. For me this meant using my background as a sociologist. It meant using my sociological imagination, as Mills (1959) put it. It meant seeing what was happening in the light of my craft and my intellectual background—it became a question of seeing how individuals construct certain social milieus and how these reference society at large (Mills, 1959, pp. 132–133). It does not mean going out into the world and testing a certain theory on empirical evidence. Instead, as Michael Burawoy has put it, it is about using an extended case method to connect the personal troubles of the milieu to the public issues of social structure (Burawoy, 2007; Burawoy et al., 1991, p. 6). It is a question of seeing the reciprocal nature of face-to-face interactions and larger societal tendencies as they inform and influence each other.

Now, I am not going to have an in-depth discussion of my ontological or epistemological position here, but suffice to say that, like the rest of my research, this position is a bit messy. Using my sociological imagination and going about this as a form of detective story is an attempt at uncovering or unearthing a “reality” that is both partially hidden and complex. As this article is part of a larger, now finished, dissertation, I develop my ontological discussion further elsewhere; but I will still position myself here. I am predominantly working within a critical realist position (Bhaskar, 2016), though without swearing any form of allegiance to it. By doing this, I have, through the work presented here, attempted to discover different tendencies and mechanisms that may have enabled our current culture of grief. However, this position and its “deep” ontology or realism is not, as many would believe,<sup>6</sup> necessarily incompatible with more discursive or even post-structuralist positions. Indeed, using a more discursive and ethnomethodological approach to the world is in no way detrimental or opposite of a critical realist position. This is a large discussion concerning the nature of reality and how we conceptualize it, but for the sake of this article’s argument, it should be enough to say that my position is in between these. I see the social as discursively constructed, but the nature of “reality” as such is always just out of our reach; thereby “reality”<sup>7</sup> becomes the condition of possibility for the world as it is. What differentiates these positions, such as post-structuralism or discourse theory and critical realism, is a complex question with complex answers, but they are not wholly incompatible as Roy Bhaskar and Ernesto Laclau have discussed (Bhaskar & Laclau, 2013). Basically, it boils down to whether or not you see reality as completely discursive or if there is something “real” out there, before our descriptions of it—Laclau would argue that what Bhaskar calls reality, and

the scientific endeavor to uncover it, is a discourse in itself and thus not an attempt at uncovering reality, but only creating it. Conversely, Bhaskar would claim Laclau is committing an epistemic fallacy by taking what is seen or what exists in language as everything, thereby conflating our discursive construction of the social with “reality.” For the sake of this article, I am looking at how something is discussed and talked about as my empirical evidence—thereby necessitating a methodology such as the one in gonzo research.

Doing this requires intellectual craftsmanship (Mills, 1980), which entail three things: (1) no division between theory and method, (2) no division between work and life, and (3) a reservoir of materials one can draw on (Ingold, 2011, p. 240). For Mills, this last point comes in the shape of notes that contain “fringe-thoughts” from everyday life, experiences, conversations from a variety of places, and even dreams (Mills, 1980, pp. 64–65). The first point entails the work I’ve done, since working in the manner I have, calls for a constant back and forth between what I’ve done—i.e. my gonzo approach—and the theories I apply in my work. This means that the “mucking about” I mentioned earlier and the breakdowns I experienced, led me to certain theoretical ideas that developed as I made my way into the field of grief research in Denmark. It also accounts for what you are reading right now, which has no clear distinction between what I did, how I did, why I did, and what I learned. Using gonzo research as an approach demands a certain way of telling about one’s findings that are at once narrative, methodological and theoretical. This also accounts for Mills’ second point, which is something many researchers probably experience: My research became a huge part of my life, everything was suddenly empirical evidence, and it required some skill to separate the two. Doing gonzo research is, to some extent, a “way of life” or more precisely a “way of life and research.”

Of course, what I am looking at, that is, the phenomenon in question, is not a completely new discovery. The fact that psychiatric diagnoses are contested is not news-worthy any longer. Thus, I am fully aware of the work done by others in a similar vein as mine, either as personal narratives of the problems inherent in the DSM-5 as described by Allen Frances in his work, *Saving Normal* (Frances, 2013) or explorative critiques as in Gary Greenberg’s, *The Book of Woe* (Greenberg, 2013). Even works such as Emily Martin’s, *Bipolar Expeditions* (2007) cover similar ways of approaching a phenomenon and the work of Allan Horwitz and Jerome C. Wakefield in *The Loss of Sadness* (2007) has also aimed important critiques at psychiatric diagnoses before. Furthermore, the research group I am a part of is, in some ways, a continuation of a previous research group on Diagnostic Cultures (Brinkmann, 2016; Brinkmann & Petersen, 2015; Brinkmann et al., 2014). Therefore, the story I am telling is not completely new or wholly original, but the reason for this story needing to be told is that it is about a new diagnosis and because the story plays out in a specific Danish context. I am thus aiming at telling a story and by doing so both highlighting the problems with the implementation, the difficulties of doing the kind of research I have been

doing and furthering a particular way of reporting and doing said research—that is, through gonzo research as a concept, which I will explain further now.

### Going Gonzo

I would argue that working in this manner is a form of abductive reasoning. As Brinkmann has pointed out, abductive reasoning is used in uncertain situations where something is happening that needs to be understood or explained (Brinkmann, 2014, p. 722) and this is almost precisely how the beginning of my research was. The second thing I mentioned that became important for me was the notion of “gonzo sociology.” This has to do with the *how* of the abovementioned reasoning—the way in which I collected empirical evidence. Gonzo is a reference to the form of journalism mostly associated with Hunter S. Thompson and the books he penned, wherein he applied this form of reporting; most famous among them are *Fear and Loathing in Las Vegas* (Thompson, 1971) and *Hell’s Angels* (Thompson, 1967). As a form of research method, gonzo is focused on similar dogmas as the ones in Thompson’s work: The point is to go out into the world and “do it” (Wozniak, 2014, p. 454), relying on first-hand narratives and ethnographic immersion into areas that are messy, complicated and perhaps even dangerous. Now, while I don’t claim to boldly go where no one has gone before as a sociologist, the reason for choosing this method has to do with its aim. Since it is inspired by a form of journalism, gonzo sociology aims to “*combine the art of the journalistic endeavour with the method and theory of the academy*” (Sefcovic, 1995, p. 33). By doing so, gonzo sociology is a form of participant observation and a specific form of ethnography that has a strong emphasis on the researcher’s experiences in the field.

This divide between journalism and academic discipline need not be so vast, if we take into account Albert Camus’ notion of what journalism ought to be: Critical, done by thinkers, and not just blindly relaying information (Camus, 1991, pp. 52–54). Now, there is a rather large and ongoing discussion about “public sociology,” which has many similarities with what I am doing here. As far back as the book I referenced earlier by Burawoy et al. (1991) all the way up to Burawoy’s presidency of the ASA there has been a heated debate as to what extent sociology should be public in the sense that Burawoy argues. I am not a declared “public sociologist” and I am not working within the explicit framework of public sociology—I am sketching a critique and I am writing in a style that may or may not engage or appeal to a larger “public” debate, but I am still primarily a sociologist and I don’t find the distinction between “professional” and “public” sociology all that helpful. I am using this gonzo approach because it allows me to not: “*(...) be constrained by abstract codes that have no relevance outside the scholarly professions, nor from taking authentic, compassionate, and liberating actions*” (Sefcovic, 1995, pp. 33–34). This allows me to do two things: First, it makes it possible to write this story as close as possible to the way it actually happened, and second it allows me to see part of

my research as a journalistic endeavor, wherein I attempt to reveal something—in this case how and why the implementation of a psychiatric diagnosis broke down. Once again, it is pressing that I note how this way of going about things was not planned out in advance. I whole-heartedly admit to the messiness of my methods (Mellor, 2001), but I also believe that this messiness is what made my findings interesting. To reiterate: the story I'm telling is framed this way because it makes sense. Returning to abductive reasoning, what I bring forth in the following are the elements of my data that could give a sufficient answer to uncertainty—the points of empirical evidence that might help resolve the mystery. These are the elements of my observations that might help answer the question: what happened with the diagnosis in a Danish context, and what might this tell us about diagnoses? I am not saying that my findings give a satisfying answer to all of the sociological questions one might ask concerning Prolonged Grief Disorder, but I am saying that what my field work has shown is that the implementation of such a diagnosis is fraught with the exact same messiness as my own research.

### The “Data”

During the last 3 years I have attempted to investigate the academic—and, in part, more public—field of grief. I participated in a grief counselor education program offered by the Danish National Centre for Grief. I also participated in network meetings between grief researchers in Denmark and network meetings concerned with Prolonged Grief Disorder specifically. I attended conferences on grief, hosted by the Grief Centre. I gave talks at conferences for GPs about grief, I gave talks for other researchers working with grief or diagnoses in general, and so on. I also talked to people involved with grief research in the breaks between meetings, conferences and so forth—what you might call water cooler research. I received emails from people about the situation, hints, and gossip at events I attended and so forth. My empirical evidence is thus a bricolage of different things—some long and insignificant, others extremely significant and observed or said to me in secrecy or in passing. This means I do not have any recorded semi-structured interviews. Instead, I have field notes, jotted down while something was happening or being said or shortly after, emails, and quotes I wrote as I heard them. I constantly carried a notepad with me (I still do) and whenever something occurred that may have had any interest, I wrote it down. This led to around 100 pages of handwritten notes, that had been scribbled down over the course of my fieldwork. I wrote them while listening to others give talks, or I would discuss something with someone and then quickly recede to a place where I was able to write things down. I would write down not only quotes that I had heard, but also moods and settings. How was the mood in the room, what were people wearing, at what kind of a place did it unfold? Often, I would write what I thought was most odd about a situation and reflect on what that made me feel or think—initially this was a “technique” to jog my memory, but as I came closer to embracing gonzo research as a

viable option, these observations became essential for my work. After an event, if I was unable to write down during, I would find place afterward where I could drink coffee and smoke cigarettes, while I wrote down all the things I could recall as fast as possible. I wanted to avoid the look of a blue-eyed researcher or journalist that walked around with a notepad in front of his face—instead, I opted to soak it up and write things down in breaks. There is no doubt that I am open to critiques of rigor in this sense, but what I am trying to do with my work and this article in particular, is to describe both a process of realization through this gonzo approach that is a type of autoethnography (Harmon & Dunlap, 2020) and what this approach led to. It is a combination of both analytical and evocative autoethnography, but heavily leaning in the latter, which also means there is no clear “structure” to my notes and instead it is told as a story that might evoke certain feelings; both concerning what it is to do this type of research and what my research shows.

Then, what about the ethical aspects? If things are told to me in secrecy and some of it is gossip, can I even use it as data? I'll resolve some of this by anonymising the individuals I talk about. When it comes to things such as gossip and secrets, these will also be drawn upon; both because I won't reveal from who I received such information and also because the individuals I talked to knew I was researching what was going on—perhaps this was even their reason for telling me this information. I would argue that I, in some instances, became a stranger to the milieu I investigated—someone who is *in* the group but not *of* the group, stuck in between nearness and distance (Simmel, 1950, p. 404). While one might intuitively dismiss gossip and secrecy in research, things like (confidential) gossip is extremely important in organizations (Brady et al., 2017; Fan et al., 2020; Michelson & Mouly, 2002). And as Norbert Elias and John Scotson found many years ago, the structure of gossip is particularly important for different groups (Elias & Scotson, 1965, pp. 104–105)—and it also turned out to play a role in my own research. I went into this field of research to figure out what was going on, and I also used myself as an element in the research—that is, by observing how I was viewed by other researchers, how they reacted to what I was doing and saying, and also what was said behind my back. In the following, I will tell the story of how these things became clear to me during my research, thus showing how I stumbled into gonzo research and what this approach revealed.

## Part 2—Eureka and Being Watched Over

### The Quarrel

It is January 10, 2019 and I am 8 months into my time as a Ph.D.-student. So far, I have learned that the diagnosis I was supposed to research hasn't been implemented in Denmark yet, and that it won't be for quite some time. The working group in charge of creating the National Clinical Guidelines (NGC) has been working on them from 2018. In Denmark, these NCG are “systematically developed, professional recommendations

meant to be used by health-care workers” (Sundhedsstyrelsen, 2019 *my translation*). They are mostly developed by the Danish Health Authority through working groups with specific knowledge about the given topic of National Clinical Guidelines—however, it has recently been made possible for other professional interest groups and environments to apply for money to create their own working groups. Such is the case for PGD, where the Danish National Centre for Grief<sup>8</sup> received funding from the Danish Health Authority to develop said guidelines. On this date, I attended a network meeting for researchers, GP’s, psychologists, and more with an interest in diagnoses and this meeting was on the topic of PGD. I had been invited to give a talk about my research, which was very much in its infancy and I was filled with my own perpetual self-doubt. As the meeting played out during the day, it slowly became clear to me who I was in a meeting with—several members of the working group developing National Clinical Guidelines about PGD were attending. At this time, I had only been aware of the problems with the working group through gossip and hearsay, but this meeting gave me a clear view of their disagreements.

When the first half of the meeting was done, talks had been given on the diagnosis by what could be characterized as “proponents” of it—that is, a specific researcher that had a pragmatic approach to the diagnosis (“*we just have to swallow the diagnosis*” was the wording used)—and by their proponents; probably best summed up in the metaphor aimed at the work with the diagnosis: “*Getting wet only became a problem once the umbrella was invented.*” Then a clinical psychologist gave a talk that encapsulated a lot of the problems. The framing of her talk was initially a critique of a newly founded grief counselor education program, based on an article written about it (see Witthøfft, 2018). It quickly turned into a scathing critique of the entirety of the National Danish Centre for Grief and their work, the breakdown in the working group developing the National Clinical Guidelines, and the diagnosis in general. “*Prolonged Grief Disorder is society and the system’s disease.*” she proclaimed—while researchers and members of the Danish National Centre for Grief protested. “*I don’t understand this critique at all,*” one of them said, while shaking her head, “*What else should we do? We should use what works.*” Two other members of the National Grief Centre protested as well, “*The grief counsellor programme is NOT a treatment-oriented education.*” The clinical psychologist became increasingly annoyed, her face turned red and as more participants got involved, the discussion became heated. Two sides were clear: individuals involved with the Grief Centre and everyone else. Everything from the diagnosis itself, to the way it was being implemented, to the grief counselor education was discussed. Was it a “real” diagnosis? Was there enough empirical evidence for its existence? Why did the Danish National Centre for Grief want to implement it so quickly? Was the grief counselor education a new treatment-orientated education provided by the Grief Centre? Would all these new implementations and educations “ruin” the existing forms of grief counseling? “*It is a scandal that people die without a diagnosis,*” a GP ironically proclaimed during his talk, “*And I know she is trying to sell*

*cars and has to work with that,*” he continued—referencing a researcher from the National Grief Centre. As this argument unfolded in front of me, I realized that *this* was the reason the guidelines had not been finished—there were massive disagreements of all sorts in the working group. Existential, professional, and even personal disagreements were abundant. This was one of my most substantial eureka-moments (Locke et al., 2008, p. 908) during my field work and helped me further my research and reasoning throughout—I realized that I couldn’t go about this in a conventional manner, and instead I needed to figure out who was involved in this argument and the breakdown in the working group. I needed a methodology that allowed me to deal with doing research in a politicized field.

Afterward this episode was referred to as “the quarrel” by the small group of grief researchers and people involved with PGD in Denmark. Now, I’m not saying this sort of thing happens with every new psychiatric diagnosis, but it does lend credibility to the idea of such diagnoses as epistemic objects (Brinkmann, 2015; Danziger, 2003). This means that PGD, is not an essential entity to be found within an individual, but likewise it is not a wholly socially constructed entity. Instead: “*The coming and going of such categories is not the story of ‘a mirror to nature’ that yields ever-more accurate reflections but a much more mundane story of social interests, everyday practices, and human preoccupations*” (Danziger, 2003, p. 28). What I discovered through my research, exemplified acutely in “the quarrel,” were precisely these social interests, everyday practices, and human preoccupations—but also personal disagreements and interests. When I talk about these things to people outside of grief research, their first reactions are always of doubt and bewilderment “*But, the diagnosis is a tool for helping people.*” as one psychologist said. “*I’ve been a doctor for many years, and I will never use this diagnosis in my practice*” a GP told me at a talk I gave. “*It seems ill-considered to implement something like this?*” a hospice-worker said at the grief counselor education program. “*Why implement it when there’s so much disagreement?*” I was asked by a nurse at another talk. My task through my gonzo research became to reveal these problems and gauge the reactions of people unaware of the troubles with the diagnosis.

### The Cure

Before “the quarrel,” on September 18, 2018, I attended the Danish National Centre for Grief’s first conference. I had been a Ph.D.-student for just shy of 5 months and I knew few of the key-players. When the conference was over, I had a clearer view of this. I remember arriving as a lowly PhD-student and writing in my notes: “*This is a very prestigious place and event.*” The conference counted around 450 participants with keynotes from the most significant grief researchers in Denmark, as well as a keynote by Doctor Katherine Shear. The conference was a signal—it was a way of saying: “This is our domain, and we are the grief researchers in this country.” At the time, I was still not fully aware of the problems between many

of the players, but several things struck me as odd. Initially, the sheer scale of it surprised me—so many people were attending, and the event was held at the Maersk Tower,<sup>9</sup> which was very new and a very expensive place to rent. Everything was new, everything was filmed, and everything was, to me at least, rather peculiar for an event concerning grief—an emotion usually relegated to the private life. As the keynotes were given, I began realizing that they were all—except one—pointing in much the same direction: How can we assess who potentially could develop Complicated Grief or Prolonged Grief Disorder? *“This is the world’s biggest grief study!”* one of the keynotes said. *“It is a judgement call,”* another said when referring to the differences between the Inventory of Complicated Grief scale and the Prolonged Grief Disorder scale. Slideshows were shown to the crowd, filled with data results, numbers and arguments for the validity of psychometric tests and results—as I looked around, I wondered: *“How many of the individuals in this room, have a clue what those results mean?”* In a short video of the event, published afterward, the director of the Danish National Centre for Grief explained that the point of this conference was to gather and communicate knowledge about PGD, both how to treat it, detect it and prevent it.

I was confused. I had gone to a conference on grief, and I came out with a feeling of having participated in a conference specifically about the diagnosis of Prolonged Grief Disorder—with a lot of talk about Complicated Grief, which either was or was not the same; *“It is a judgement call.”* Except it wasn’t really a judgment call, as the debate between which criteria where the “best,” most “precise” or “correct” was ongoing (Maciejewski et al., 2016). This all happened before “the quarrel,” but it was at this event I got my first inkling about the problems with the National Clinical Guidelines. There was a politeness between everyone, researchers from my own group, researchers connected to the Danish National Centre for Grief, researchers from other groups—but there was still a sense of this friendly demeanor hiding something. A sense that people were eyeing and keeping a watch on each other. I was a completely unknown researcher (I still am) and at that point I could walk about at such a conference, without anyone from the community of grief researchers knowing who I was.

While I was doing so, I was introduced to a GP, who seemed even more confused than me—and a lot more annoyed. I learned he was part of the working group developing the National Clinical Guidelines and I also learned that he was not pleased with what he was seeing—perhaps best summed up in a story from the conference he relayed to me: *“I just came from a smaller seminar,”* he said, *“and someone in the crowd asked the presenter: ‘So, how do you get un-diagnosed? When are you cured from it?’ And you know what the answer was? Silence!”* For the GP, this story was probably the best thing that had occurred all day. It meant that we had arrived at a point in time, where you could get diagnosed with something, but how to get rid of the diagnosis or how best to treat it was unknown. Now, it certainly isn’t unusual that diagnoses come into being without a clear way of treating it, but it was unusual that so many researchers were scrambling to define treatments

and guidelines for this diagnosis, when one of the proponents of the diagnosis couldn’t give an answer to how you knew when someone *wasn’t* suffering from PGD any longer, after being diagnosed. But the GP’s story also showed me something else: that nobody agreed on anything. He eagerly told me how this diagnosis and the work being done was built on shoddy evidence and that the proponents were only interested in money and in “winning” the struggle to define grief *“It’s a joke,”* he proclaimed, *“They’ve just given the rights to define what grief is and is not, to a private organization.”* The GP himself was simultaneously critiquing this struggle and a part of it.

This meeting became important, because I learned something about the positions in the pending discussion on the diagnosis, but it also made me aware of the difficulties I would have, concerning access to this field (Matthiesen, 2020). I would not be able to stand on the side-line or observe from any sort of objective vantage point—I would have to gain access to these discussions as I went along and I would have to employ myself as a research object (Matthiesen, 2020, p. 13). I would have to attend in as many events concerned with grief as possible and be where people involved with PGD would be. This meant that I would not just observe the community or field of grief research in Denmark, I would participate in it and thus produce the field through my ongoing engagement with it. None of the people I investigated simply *were* roles or participants, like I was not just a particular researcher observing a field—instead, my engagement with this field was a question of becoming rather than of being. By this meaning that there was no clear case to research with a start and end, or a sense of me *being* a researcher, but rather of sense of me *becoming* a part of the field and my research, as has been described by Elisabeth St. Pierre (2011, 2013, 2019). As I struck up conversations with individuals, presented my work, voiced my concerns and findings, and listened to discussions or what people told me I was slowly gaining access. But I was also becoming enmeshed in the field—simultaneously engaging and creating what I was researching. I was not a distant observer but a participant in the ongoing field of grief research in Denmark and I needed a methodology and a way of tackling this that made sense, thus opening the door for seeing my research as a form of gonzo research.

### *Being Watched—Politics of the Field*

Three months after “the quarrel” I attended a meeting in a national grief researcher network and this time my own research group were the hosts. I was asked to present my project. *“What project?”* I thought to myself. I still had nothing really to go on except hunches and hearsay. I agreed and prepared a talk, which revolved around vague notions of me discussing how we might sociologically understand the diagnosis as a phenomenon specific to our contemporary society (Lund, 2020a). I also presented another leg of my research, which at that point, I did not fully grasp what I wanted to do with. As mentioned above, “the quarrel” revolved around several aspects of the diagnosis, but it began with a scathing critique

of The Danish National Centre for Grief's new grief counselor education. After having surrendered myself to the absurdities of not having a clear research object, I decided to follow the smoke and tried to get access to the education program—which turned out to be fairly straightforward, since one of my supervisors' name, Svend Brinkmann, always gets people's attention. In an essay, Thompson (1979) discusses his *Playboy* Magazine tag and how it opens doors and gives him access; "*Pure Magic*," he calls it. While the name, Svend Brinkmann, isn't pure magic, it does get people's attention and opens doors. The reasons for wanting to observe and participate in the education program were varied—partially because I wasn't sure what I was looking for. I wrote to the participants and the course coordinator asking for permission to join the program, telling them I was interested in the education, but also the people participating. Both goals were vague enough to not elicit any further questioning. What I really wanted to figure out was what they were teaching people—was the aim of the program to further implement and emphasize their conception of PGD and Complicated Grief?

Anyway, at this network meeting, I gave a very short and deliberately unclear talk about my project. Most of the people attending were from my own research group, with a few other interested researchers. There was, however, one person in attendance from the Danish National Centre for Grief—a researcher who had been recently hired by them and who was attending her first network meeting. As I gave my 20-min talk, laying out how I was interested in the diagnosis, the grief counselor education, the culture surrounding grief and so on—I saw the researcher scribbling away on a notepad. Prior to the meeting I had talked with my supervisors about keeping my presentation somewhat fuzzy and not criticize too explicitly the education, so I wouldn't stir up any trouble or lose access to the education. I made no mention of "the quarrel," or my sense that something was rotten in the working group, or that the education specifically said that it was meant to improve the participants' knowledge about Complicated Grief—their website lists five bullet-points and three of these pertain to Complicated Grief (Københavns Professionshøjskole, 2020). I kept everything vague, and simply talked about my very general ideas—as mentioned this was easy since I did not really know what I was looking for at this point.

But what happened afterward was interesting: a little less than a month after my presentation, I got an email from my contact at the grief counselor education program. It was very polite, of course, and started off with questions about what I had learned so far and if I wanted to give a talk at the program, but it ended with something else. "*I heard you gave a talk at the network meeting for grief researchers where you talked about the education—maybe more about the diagnosis—but you coupled the two things. I have a few questions for you regarding that.*" I went back to my slides from the day and ferociously scrolled through them, looking for anything I might have presented that could be understood as critical. I couldn't find anything. At first, I was confused: "*How does she know what I talked about?*" And then I remembered the one person

from the Grief Centre who had been in attendance. All the notes that had been scribbled down while I was giving my talk had been reported back to the center. They were keeping an eye on me—and perhaps even my whole group—and so I was asked to come talk about my talk.

Now, there was nothing threatening in the e-mail, but I did get the sense that they were making sure that I would not cause any trouble. It was a form of pre-emptive damage-control. And this emphasized my experiences from the conference and my meeting with the GP. I had to use these things explicitly in my research. I would have to write out how I became involved with this field—the power relations that surrounded me, my identity as a researcher and how I negotiated the field (Giampapa, 2011). At this point, I was very much aware of my non-position as a distant observer. Playing it safe with my talk still led to questioning. I knew, like every other researcher, that what I did in the field would have consequences—that's why I played it safe with my talk—but it had not yielded the results I had expected. As a sociologist—and I often refer to myself as a critical sociologist—my work has always sought to examine and criticize power structures, but after this it became painfully clear to me that I needed to put my critique more into action. I needed to be vocal about my critiques and to use my research in the field as a way of putting myself in the thick of it.

At this point I began referring to what I was doing as Gonzo sociology and the Thompson quote began rattling around in my brain: "*When the going gets weird, the weird turn pro*" (Thompson, 1980a, p. 36). I'm not arguing that I fully live up to Thompson's designation of being either pro or weird, but I did find inspiration in that quote—things did get weird for me pretty fast, and I had to turn my approach upside down and radically change what I was looking for. I was not "just" researching something, I was actively a part in what was going on and I was attempting to uncover something—both when it came to my own research, but also regarding how this implementation had gone awry and was fraught with problems and inconsistencies. My experiences, my failed attempts at getting access, the gossip I received, the way I was "watched over" was the research.

## Part 3—Money, Gossip, and a Failed Experiment

### Back to School

After the events and experiences described in Part 2, I began embracing this style of working more. My notes became more thorough, and I sought these things out more actively. I would participate in things and deliberately explain what I was doing, both at talks and presentations, but also in the coffee-breaks and at conference-dinners. I would be vocal about the problems I had heard of, the fact that I was being surveyed by the organization, and the rumors I heard about the working group's breakdown over the National Clinical Guidelines. The grief counselor education program became a place where I could test this approach out, while also getting closer to the

organization in charge of said working group. The education consisted of five, 3-day modules, each with their own specific focus. I attended most of it, and participated in discussions, lunches, and coffee-breaks and even gave a 3-hr talk one of the days. The biggest reason for being there, was to figure out how grief was discussed—both by the teachers and by the participants. How big a focus was on Complicated Grief? Especially considering the trouble with PGD and Complicated Grief I had observed elsewhere. After having gotten the OK from the director and vice-director of the Grief Center, along with written agreements by all the participants, I could begin the program.

I began by presenting myself and then just sitting with the class—initially this was fine. However, as days went by, I was slowly positioned as an “expert” by both the students and the teachers, sometimes specifically referring to me with questions or insights, and I played along. As I said, I had a goal with being there, which was to figure out how big a role the diagnosis played. Without ever saying this out loud to anyone else than my supervisor, it still became clear to everyone there that this was my position. I was already being kept an eye on when it came to what I said and a lot of discussions about the diagnosis at the program involved me as well. I was placed in the position of the critical researcher by teachers and members of the Danish National Centre for Grief and as time went by, I also took on this role myself. The participants would involve me in discussions in class and come to me in breaks: *“What do you think of the diagnosis?”* they would ask, sensing something was afoot. An entire module was allocated to talking about it, and this was, of course, the most interesting one for me—and this module was in between my talk at the network meeting and the email I received about what I was saying. There was a substantial focus on both PGD and Complicated grief, even though “the quarrel” revolved around whether the education was about treatment or training participants to treat grieving individuals. And one of the take-aways from the network meeting was that the education was contested, but only meant as a way for “grief workers” to improve their knowledge.

“How can we prevent people from having Complicated Grief reactions?” “How do we find those who are at risk?” “Why can’t we just implement the diagnosis already?” These quotes all came from the participants, showing how the focus from the get-go was on what was framed through the whole course as Natural vs. Complicated Grief—without this distinction ever being clear. “The Danish National Centre for Grief believes in Complicated Grief and Prolonged Grief Disorder.” one of the teachers said. We watched a short movie about grieving individuals, “Would any of you be worried about them?” the teacher asked, referring to the depicted bereaved, “Do you think any of them are at risk of developing Complicated Grief?” It was, seemingly, very important that the participants learned to differentiate between natural and Complicated Grief reactions. One of the problems with this, I learned, was that this difference was hard to explain, since there was no agreement as to what Complicated Grief really was, and the way that the Danish National Centre for Centre described it

was criticized heavily by other organizations. In fact, this was one of the reasons the working group broke down, while they were making National Clinical Guidelines. All of this wasn’t talked about at the program. There was, to me at least, a somewhat absurd discrepancy between what was being said at the education program and what was happening among the field of grief researchers in general.

Now, I’m not saying that the whole program was a sham or anything like that—there were lots of good and interesting perspectives—and I am also not saying that this education is solely responsible for the “spread” of Complicated Grief as a concept in society at large. But I was taken aback at the very pronounced focus that the education had on something that no one really had a clear view of what was or is. I was the odd one out, because I had an inkling about what was going on and because they knew I was there. They were hesitant with their statements and descriptions and I kept wondering if the focus on Complicated Grief and PGD would be bigger had I not been there. As I took a step back and looked at the landscape of grief in Denmark, I noticed that programs like this one had popped up all over. You could now become a Grief Counselor (Københavns Professionshøjskole, 2020), a Certified Grief Counselor (Seminarer.dk, 2020), Grief and Crisis Therapist (Krise & Sorg, 2020) and so on. They all focused on PGD and Complicated grief and they all had different conceptions of it. Grief had become an arms-race to put forth the best conceptualization of grief and teach individuals about it.

### Gossip

I realized this through gossip. My own research group was involved with figuring out what grief was and what it said about the human condition. My part of this was looking at the social conditions of grief and taking a critical look at the diagnosis. There was no focus on treatment, prevention, risk-groups and so on in our research-group. *“They just got a lot of money and are not doing any real research,”* other researchers gossiped about us, as relayed to me from another researcher in the grief community. Our group wasn’t doing “real science” and we were being discredited for it. *“Have you heard that they’re making their own working group now? So they can develop their own National Clinical Guidelines,”* a confidant told me at a conference, while showing me their invitation to participate. As my research progressed, these disagreements became more pronounced.

My access to some places benefited greatly from the “magic” of my supervisor’s name—but conversely that same name and the research group it represented, closed many things off for me. And this is what the gossip taught me: That research is not apolitical. By this I do not mean that certain political parties benefit from highlighting or suppressing different forms of research (though this is also a very relevant discussion), but rather that what research is and does practically is not value-free. My research, somewhat by my own design and way of being, became a value-laden way of seeing this. The proposed objectivity of something like PGD was revealed as a frail

narrative kept alive by researchers arguing for more “real science” while dismissing the work done by researchers like myself or my research group. And this argument was not only bound to the very micro-scale interactions I waded through, but also at a national and international level. Indeed, as Leeat Granek has pointed out, we might even see the entirety of the current psychological research on grief as a symptom of an academic discipline gone awry (Granek, 2014). We might also see grief as politicized, not only as a form of politicized mourning that fights injustice or motivates the fight for social justice (Butler, 2004; Granek, 2014), but also in the sense that who gets to decide what grief *is* and how it is treated, is a political game.

Stumbling into this field the way I did was difficult, but it was also necessary. How else would I have known what to do with gossip like the abovementioned? How else would I have known how to write out what I found? I’m still not even sure that what I am doing right now, writing this, makes sense. As Thompson himself wrote about his arguably most famous work: *“Fear and Loathing in Las Vegas is a failed experiment in gonzo journalism”* (Thompson, 1980b, p. 95), but that this failed experiment is still worth publishing: *“(...) it’s not what I meant it to be, [but] it’s still so complex in its failure that I feel I can take the risk of defending it as a first, gimped effort in a direction (...)”* (Thompson, 1980b, p. 97), which is “new” and does something interesting with journalism. While I don’t claim to reach the greatness of Thompson’s work, I do still find solace in the fact that his greatest work was also a failed experiment. Perhaps my way through the research I have done is also a failed experiment, that, despite this, is still interesting enough to discuss.

Why is it interesting? Because it shows something important when it comes to the way we grasp diagnoses and specifically the way in which we are treating grief: that they are not necessarily essential, objective truths. They are always reciprocally produced by and producing the social. The problems then arise when we lose sight of this and want to do good: *“The problem is that a toxic combination of vested interest and good intentions produces continual pressure to extend the range of abnormal, shifting the demarcation point further into the territory previously considered normal”* (Heath, 2013, p. 1). All these organizations and individuals want to do good. They want to help; they want to relieve the pain and suffering of grieving individuals. But wanting to do this becomes problematic when it involves money, professional pride, and personal differences. The gossip I heard shows this. My research group was given money, but we weren’t using it to help people or do proper research (i.e., research involving quantifiable data or evidence-based psychotherapy etc.) and so we were discredited. Others were angry that they did not get the funding they wanted, and that it was given to others—creating a rift in the community of researchers. From the very beginning—meaning from the disagreements and discrepancies between Complicated Grief Disorder and Prolonged Grief Disorder—all the way to the competing educations and conceptualizations in Denmark, nobody really agrees on much it seems. I heard stories of how

the original researchers behind the two diagnoses hated each other and fought to get their respective diagnosis in the ICD-11 and the DSM-5. And I found similar stories locally. *“We have the biggest data set,” “That’s not proper research,” “She’s just angry they didn’t get the money,” “He has no idea what is going on.”* In short, gossip containing bickering about money, about the positions people held, and about who got to define what natural and pathological forms of grief were.

As I talked to more and more people involved in the working group developing the National Clinical Guidelines, I learned that they disagreed on everything. Two methodological consultants had left the group, because they *“(...) couldn’t vouch for the evidence or scientific validity in the research,”* as I was told by a member. I read the consultation responses to the first draft by different organizations, that gave scathing critiques of the wording, the empirical evidence, the framing... Pretty much most of it. *“They are extrapolating a badly documented effort from one group to another, even worse defined, group.”* one of the evaluations said of the draft for the NGC. How to understand this? And how to understand a lot of the actors’ willingness to gossip about each other? In my view, a lot of it has to do with being in charge—about having control of things. As Heath has pointed out, there are economic interests in diagnosing that propagate this view of suffering in general—and when it comes to PGD. It is estimated that around 10% of bereaved individuals suffer from PGD (Lundorff et al., 2017)—though the studies are of a varying quality and differ greatly in their estimates. Around 53.000 people die every year in Denmark (Danmarks Statistik, 2020) and if we set the number of close relations that will grieve a loss very low—let’s say 2 pr. deceased—around 106.000 individuals will experience grief following the loss of a significant other. This means that somewhere around 10.600 people, every year, could potentially be diagnosed with PGD in Denmark alone.

One way of understanding this, as a lot of proponents of the diagnosis do, is to talk about the large number of untreated and suffering individuals we thereby miss, if we do not have the tools to identify and treat them—they view grief as an economic problem and talk about the cost of grief (Engelbrekt, 2016), which mirrors Mary Ellen Macdonald’s argument that grief now exists within a neoliberal society where “the cost” of grief is important (Macdonald, 2019). This is another way of seeing these developments, which is more critical. From this perspective the bereaved are seen in market-terms: 10.000 people a year requiring treatment is a lot of therapy, psychiatry, and psychological help—it is a lot of money in treatment. And this notion also exists in the debate now, and a lot of the individuals I talked to would aim this critique at the Danish National Centre for Grief, with some even claiming that this was their entire game-plan: Get the money to develop the guidelines, define what treatment works, and design an education that teaches health-care workers to funnel people at risk of developing PGD or Complicated Grief reactions into your organization. However, as I pointed out, it is not just about money. The process broke down because it was about power and professional disagreements. GP’s didn’t want “another

*diagnosis*” that was too vague and broad, and they didn’t want psychologists and psychiatrists from a semi-private organization as the Danish National Centre for Grief to be the ones who decided what the diagnosis was and how it was to be treated. Different psychological organizations disagreed because they all had different conceptions about grief and the diagnosis. The Danish Cancer Society had other opinions, different research-groups argued about how to measure and how to treat it. It became a struggle for grief that was about money, power, and the rights to define a central part of the human experience, which saw the community of grief researchers and people who worked with grief bicker among themselves and resort to subversive gossip and public quarrels. All of this without most of the public being aware of it.

## Part 4—In the Absence of an Ending

So, how does one end a story like this? What is the conclusion to these past years of my life where I have been trying to untangle aspects of the culture of grief? In short, there is no real conclusion to this. If one were inclined to muse poetically over such things, it might be said that this is fitting when it comes to grief. Grief, as an individual experience, does not end—it is ongoing (Ingerslev, 2018); and similarly the struggle about grief does not end. There is no clear-cut answer to my research, since there is no clear-cut answer to either grief or the way we conceptualize, handle, control or ignore it, as a society. Grief, as a social phenomenon, is also ongoing (Stearns, 2019). Thus, what I have written out here is an account of my own process of realization of the fact that research—at least when it comes to my field—is not a fixed, coherent, and temporally sequestered object. It exists in a reality that is constantly changing. As Elisabeth St. Pierre points out, research is not about finishing, but rather it is a question of the ongoing nature of research—as she puts it, it is about the: “(...) *and, and, and* (...)” (St. Pierre, 2011, p. 620) of research. I could continue to research this phenomenon—figuring out what happens when the diagnosis is eventually implemented, researching the different educations, and so on. The implementation process of PGD in Denmark trudges along and the described breakdown has only slowed it down, leaving those involved scrambling to pick up the pieces and find new way of implementing it.

By adhering to gonzo sociology as a form of research methodology, I was able to gain insight into the ongoing struggle concerning grief, while also acknowledging the difficulties of gaining this insight—and furthermore the co-creation of my empirical findings. I was not wandering into a field of knowledge, as described by Steinar Kvale and Svend Brinkmann, as a traveler—walking around in the landscape and talking to individuals I met and thereby slowly learning about the truth (Kvale & Brinkmann, 2009, pp. 66–67). Instead, I attempted to break into a politicized field and report about it, thus co-creating what I was researching. “Going gonzo” allowed me to “*exist on the edges where academic practice meets popular culture*” (Sefcovic, 1995, p. 27), which means both that I could use this methodology to report my findings in the manner I

have done above and see my findings and experiences in relation to (popular) culture as well. Something I have done elsewhere (Jacobsen et al., 2020; Lund, 2020a, 2020b). It allowed me the tools to conduct “(...) *wild, immersive, and messy research which captures the imagination rather than speaking to narrow debates*” (Wozniak, 2014, p. 471)—and hopefully what I have written has done so. Through the notion of becoming as described by St. Pierre, to Burawoy’s extended case method and public sociology, to Alvesson and Kärreman’s breakdown driven research, to Thompson’s gonzo approach, I could “reclaim” or “rediscover” my research object and also attempt to report my findings. Grief has been described by Catherine E. Foote and Arthur W. Frank as a problem, since it is seen as undisciplined, risky and “dangerous” (Foote & Frank, 1999, p. 170) and these elements might not fit neatly into our current cultural climate that elsewhere has been described as a happiness culture (Cederström & Spicer, 2015; Davies, 2016) and as a culture that seeks to control as many aspects of life and the world as possible (Rosa, 2020). My job became to use my sociological imagination to connect my problems, the problems in the field of grief researchers and the breakdown within the working group with wider social issues like these.

If I were to sum up my what to make of this, I would argue that this article and my research in general has showed that: (1) My research—and much research in general—starts in complete confusion and one task is thus to make sense of this confusion and create a coherent argument. In my case, I tried to do this through my ethnographic immersion and gonzo sociology as a method. (2) When you research something thoroughly, everything seems to revolve or connect to your topic. Thus, I saw grief everywhere. Everything I did, in line with Mills’ description of the non-existent distinction between life and research, was about grief and it felt like everything I encountered was connected to the topic of grief in some form or other. (3) That research is political—it is value-laden in many senses. I knew this before doing this research, but it became very pronounced in my mind during this work. (4) Psychiatric disorders are constructions. They are not wholly “made up” because they do respond to something in “reality”—that is, people are suffering and have the experience that this suffering needs some form of treatment—but the way they are implemented in diagnostic manuals and in praxis are, to a great extent, socially constructed.

When it comes to grief, we might consider it a form of aporia (Derrida, 1993)—as something that is impossible to even formulate as a problem, thus making solutions impossible. Neither research, life or grief is a neat, coherent, and satisfying story—perhaps it is more akin to a tragedy. For, as Simon Critchley points out: “*Tragedy presents a conflictually constituted world defined by ambiguity, duplicity, uncertainty, and unknowability, a world that cannot be rendered rationally fully intelligible through some metaphysical first principle or set of principles, axioms, tables of categories, or whatever*” (Critchley, 2019, p. 137). We cannot know everything, and we cannot control everything either, thus life is tragic. The field of grief in

Denmark is fraught with fights over money, defining rights, and personal and professional pride. A diagnosis will have a huge impact on our way of life and its conception and implementation is a political struggle. Thus, grief—a completely integral part of human existence—is now being transformed by psychometric validations and fights in meeting rooms between different forms of proponents and opponents—all vying to either define the diagnosis and its treatment or to remove the diagnosis and not change their ways.


### Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Funding

The author(s) disclosed receipt of the following financial support for the research and/or authorship of this article: This work was supported by the The Obel Foundation [28153].

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### Notes

- <https://www.kommunikation.aau.dk/forskning/vidensgrupper/cqs/sorg/culture-of-grief/>
- The term “breakdown” is here meant to convey a methodology that incorporates: “( . . . ) encounters between theoretical assumptions and empirical impressions that involve breakdowns.” (Alvesson & Kärreman, 2011, p. 15), that is, that the process of work has broken down like a machine or an engine and not a breakdown in the sense of a mental breakdown.
- Gonzo is here referring to the works of Hunter S. Thompson and his Gonzo Journalism. I will expand on this later, but suffice to say it is a dubious word that is both a compliment and a detriment—it can mean that something is crazy, eccentric, odd and it can even refer to the last man standing after a night of drinking (Thompson, 1997). For me, it is a word that points to the style of writing and methodology—a specific form of ethnography that entails immersion, a first-person narrative, and tongue-in-cheek writing.
- Abductive here means a way of reasoning inspired by the works of C.S. Peirce. As Brinkmann (2014) puts it the abductive researcher is a: tool-user, the bricoleur, the craftsperson, as the ideal qualitative researcher. Unlike induction and deduction—both of which address the relationship between data and theory—abduction is a form of reasoning that is concerned with the relationship between a situation and inquiry.”
- Alvesson and Kärreman are inspired by Johan Asplund (1970) here, but also argue that his form of social theory was what we might call armchair sociology and thus removed from a lot of empirical data. For Alvesson and Kärreman, as well as for me, this notion of writing a good detective story must be based on empirical evidence. The mystery and breakdowns must be found in the empirical evidence and the story must be written in an interplay between theory and empirical evidence.
- See Elder-Vass (2012), Smith (2010, 2015) for both discussion and critique of post-structuralism, symbolic interactionism and so on, from a critical realist position.
- I use the term “reality” pretty loosely here, but it more or less coincides with the deepest level/domain of Critical Realism’s stratified view of the world, that is, the domain of the real.
- I will be referring to them as the Grief Centre as well.
- The Maersk Tower is an award-winning building in the center of Copenhagen housing parts of the Faculty of Health and Medical Science. It is new, expensive, and very impressive: <https://healthsciences.ku.dk/explore-the-faculty/maersktower/architecture/>

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