Journalist Fellowship Paper

Empathetic verification: covering 'Long COVID' in Norwegian newsrooms

By Hanne Østli Jakobsen

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Introduction

"Tens of thousands might be affected in a few months." These were the words of a Norwegian Long COVID researcher – an ominous subheading on the front page of *Verdens Gang (VG)*, Norway's largest newspaper, in August 2021.[1]

Front cover of Verdens Gang newspaper, 28 August 2021

The acute COVID-19 pandemic was receding in Norway, restrictions were being lifted as summer weather and vaccinations led to falling hospitalisation rates and fewer deaths. It could have been a bright moment, but the front page told a different story: don't let your guard down; the danger is still out there.

COVID-19 has consumed the world for nearly two and a half years. First came the fear of becoming sick or losing a loved one, then the disruption to our lives,

[1] Marie Golimo Kingsrød, 'Toppforsker slår alarm om barn og «Long COVID»: – Burde ikke la barn utsettes for dette', *VG*, 28 August 2021, https://www.vg.no/i/oWk3Lm.

the restrictions and economic hardship. And then: Long COVID. It's a scary thought that even when the pandemic passes, the disease might linger on – striking at random. It's also an important – and good – story for newsrooms: new, frightening, invisible, unpredictable, health related. [2]

The patient: A "Long COVID sufferer", as imagined by the program Dall-E, which creates images from text prompts. (Image: Dall-E/Boris Dayama et al.)

In Norway, journalists began asking about the possible long-term effects of coronavirus before the virus even properly took hold in the country. The first article mentioning long-term effects appeared on the website of NRK, the national broadcaster, on March 6, 2020, a week before the first national lockdown. It's been a persistent theme since.

[2] Chunhua Niu et al., 'The Influence of Media Consumption on Public Risk Perception: A Meta-Analysis', *Journal of Risk Research*, 13 September 2020, 1–27, https://doi.org/10.1080/13669877.2020.1819385.

Patients, doctors, researchers and journalists have all been trying to understand Long COVID in real time, as the condition has emerged. And so it is important to reflect on our reporting: what kinds of stories have we told about Long COVID? How did we listen to patients and to experts, how did we frame them? Are there stories we've missed?

I have studied the output of three large Norwegian media outlets – *Aftenposten*, *VG* and NRK's online edition – between January 2020 and March 2022, gathering 129 articles that made mention of Long COVID. I also interviewed two leading scientists most frequently quoted in these stories, and interviewed three of the most prolific authors of these pieces.

The goal of this essay is not to critique newsroom choices made in an extraordinary situation, but to learn from them. My hope is that these reflections will be useful for the continued coverage of Long COVID, as well as the next disease to emerge.

What is Long COVID? What *isn't* it?

For most of the pandemic, Long COVID didn't officially exist. It wasn't until October 2021, almost two years after the virus first appeared, that the condition was given a description and an official name by the World Health Organisation (WHO):

> *"Post-COVID-19 condition occurs in individuals with a history of probable or confirmed SARS-CoV-2 infection, usually 3 months from the onset of COVID-19 with symptoms that last for at least 2 months and cannot be explained by an alternative diagnosis."*[3]

It's still a broad definition. "Post COVID" or "Long COVID" covers both months-long debilitating illness and "a high number of post-viral fatigue cases that appear to resolve spontaneously", according to a review by the British National Institute for Health Research.[4] Estimates on how common Long COVID is vary wildly: from less than 10% of COVID sufferers in some studies – or way less for some groups, like children – to more than half in others.[5,6] So the first challenge for journalists has been simply: what are we talking about?

In Norwegian media, Long COVID has many names. Early on, journalists often wrote of "long term effects after the coronavirus", before terms like "Long COVID", "late COVID" and "post COVID" started appearing. Roughly speaking, journalists have written about two kinds of Long COVID – though they themselves have not always made the distinction clear.

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[3] Joan B. Soriano et al., 'A Clinical Case Definition of Post-COVID-19 Condition by a Delphi Consensus', *The Lancet Infectious Diseases* 22, no. 4 (April 2022): e102–7, https://doi.org/10.1016/S1473-3099(21)00703-9.

[4] 'Living with COVID19 – Second Review' (National Institute for Health Research, 15 March 2021), https://doi.org/10.3310/themedreview_45225.

[5] Luise Borch et al., 'Long COVID Symptoms and Duration in SARS-CoV-2 Positive Children — a Nationwide Cohort Study', *European Journal of Paediatrics*, 9 January 2022, https://doi.org/10.1007/s00431-021-04345-z.

[6] 'Living with Covid19 – Second Review'.

First, there are persistent symptoms for those who got *seriously ill* from COVID-19, and who spent time in hospital or in intensive care units (ICU). While medical professionals and researchers have long known that such treatment can create long-term effects, it hasn't been that well-known in the general population.[7] As Tine Dommerud, a health journalist with the newspaper *Aftenposten* said, "it seemed like people weren't aware of the risks and possible side-effects of being on a respirator. It isn't common knowledge."[8]

Second, you have long-term symptoms in people who never got really sick: those who had some days of fever, or a cough for a while – but then the symptoms never went away, or reappeared. That's been even more of a surprise, said Dommerud: "It's easier to understand those who got really ill from COVID, and who still have problems with breathing or exertion or the like. They're much easier to take seriously, but we have to take seriously those who had a mild case of COVID, too".[9]

The experts: A "debate about Long COVID", as imagined by the program Dall-E, which creates images from text prompts. (Image: Dall-E/Boris Dayama et al.)

[7] Kristin Hofsø, The coverage of Long COVID in Norwegian media, experiences and reflections, phone interview, 28 April 2022.
[8] Tine Dommerud, Experiences and reflections after covering Long COVID, phone interview, 11 May 2022.
[9] Dommerud.

Kristin Hofsø, an intensive care nurse and Long COVID researcher with Oslo University Hospital, thinks the term "Long COVID" has been used too liberally by the media. In particular, she points to the fact that three different things have often been confused:

- *Acute* COVID symptoms.
- *Residual* symptoms ("It's not uncommon to be coughing two months after a virus infection", said Hofsø.)
- True long-term effects, or Long COVID.

"The term wasn't defined, so what are we talking about? It has been anything from two weeks after the onset of disease to six months. A myriad of things were being mixed," said Hosfø. Including all of this under the Long COVID umbrella can have contributed to a sense of uncertainty and fear: "It was all very un-nuanced; we started talking about Long COVID practically a day after people had been sick. And people were terrified," said Hofsø.[10]

[10] Hofsø, The coverage of Long COVID in Norwegian media, experiences and reflections.

The science of scary

During a crisis like the COVID-19 pandemic, the public turns to news to manage uncertainty: we need information, we need to know what to do – and journalism can be a bridge to those who have that information (politicians, researchers, doctors).[11] But, the media can also "substantially influence individuals' risk perception and concern about viral outbreaks [...] in ways that are *disproportionate to the actual risk* indicated for most people" (my emphasis).[12]

This is partly due to how journalism works. As the old adage goes, "if it bleeds, it leads" and, in the case of Long COVID, we're talking about a new, mysterious, sneaky and potentially debilitating condition. These are classic features that make something "newsworthy".[13]

However, "newsworthiness" isn't necessarily a good indicator of importance. LaFountain has argued that these news criteria can bias the audience's risk perception: "Catastrophic events and mysterious fatal illnesses are more interesting than mundane, everyday risks".[14]

Why is it that the catastrophic – the scary – is more interesting than the mundane? Psychologists have studied how we humans process information and evaluate risks for decades. The main takeaway seems clear: we are not rational. Information is mixed with assumptions and emotions when we try to make

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[11] Tsz Hang Chu, Tien Ee Dominic Yeo, and Youzhen Su, 'Effects of Exposure to COVID-19 News and Information: A Meta-Analysis of Media Use and Uncertainty-Related Responses During the Pandemic', *Journalism & Mass Communication Quarterly*, 4 January 2022, 10776990211068856, https://doi.org/10.1177/10776990211068857.
[12] Chu, Yeo, and Su.
[13] David M. Secko, Elyse Amend, and Terrine Friday, 'FOUR MODELS OF SCIENCE JOURNALISM: A Synthesis and Practical Assessment', *Journalism Practice* 7, no. 1 (February 2013): 62–80, https://doi.org/10.1080/17512786.2012.691351.
[14] Courtney LaFountain, 'Health Risk Reporting', *Society* 42, no. 1 (1 November 2004): 49–56, https://doi.org/10.1007/BF02687300.

sense of the world. This is especially true of lay people, who evaluate risks mostly according to "subjective perceptions, intuitive judgements, and inferences made from media coverage and limited information".[15] We call them "biases" – mechanisms that make us pay attention to particular bits of information because they touch *something else* in us. In the words of the writer Eula Biss: "[r]isk perception might not be about quantifiable risk so much as it is immeasurable fear. Our fears are informed by history and economics, by social power and stigma, by myths and nightmares. And as with other strongly held beliefs, our fears are dear to us."[16]

"I heard of this thing…" (The availability heuristic)

"People assess the […] probability of an event by the ease with which instances or occurrences can be brought to mind," according to psychologists Daniel Kahneman and Amos Tversky, writing in 1973.[17]

The availability heuristic is one cognitive bias that affects health reporting. It's also called the familiarity heuristic, and it tells us that the more *available* (or familiar) information about a risk is, the more likely it is that we will perceive it as a *personal* risk.[18] Niu et al. concluded that this is especially true of health risks.[19]

This mechanism is one of the things that makes anecdotal evidence so convincing: a vivid anecdote ("that young teacher still can't work, even though

[15] Hye-Jin Paek and Thomas Hove, 'Risk Perceptions and Risk Characteristics', in *Oxford Research Encyclopaedia of Communication*, by Hye-Jin Paek and Thomas Hove (Oxford University Press, 2017), https://doi.org/10.1093/acrefore/9780190228613.013.283.
[16] Eula Biss, *On Immunity: An Inoculation* (Fitzcarraldo Editions, 2015).
[17] Amos Tversky and Daniel Kahneman, 'Availability: A Heuristic for Judging Frequency and Probability', *Cognitive Psychology* 5, no. 2 (1 September 1973): 207–32, https://doi.org/10.1016/0010-0285(73)90033-9.
[18] Hye-Jin Paek and Thomas Hove, 'Risk Perceptions and Risk Characteristics', in *Oxford Research Encyclopaedia of Communication*, by Hye-Jin Paek and Thomas Hove (Oxford University Press, 2017), https://doi.org/10.1093/acrefore/9780190228613.013.283.
[19] Niu et al., 'The Influence of Media Consumption on Public Risk Perception'.

she only had a mild case of COVID") will have a more prominent place in our mind, making us prone to over-emphasising it when we think about the *overall* risk of Long COVID.

Examples from real life is something that LaFountain warns could bias us: "People often draw incorrect conclusions from anecdotal evidence", and will give it weight, even if it's not "a good representation of actual levels of risk".[20]

"It freaks me out" (The affect heuristic)

The affect heuristic is closely related to the availability bias. This is the mechanism by which a risk that arouses dramatic feelings – like anger or fear – is likely to be seen as more common: "If we feel intense dread when we perceive a risk, we are likely to evaluate it as more threatening and more prevalent".[21] The intensity of that feeling makes the event – or the news story – more available, i.e. easier to remember.

Interestingly, it doesn't necessarily mean that it will be remembered *correctly:* Wahlberg & Sjöberg stress that dramatisation negatively influences recall. If a piece of news is presented in a dramatic fashion, people will remember less of the facts and the complexity of the story than if the "drama" is toned down.[22]

"But what is it!?" (Fear of the unknown)

Uncertainty is a stressful state of mind. To give just one example: experiments have shown that people experience higher levels of stress when they are told they have a 50-50 chance of getting a small electric shock, than when they are certain they will get it.[23] Nicholas Charleton, a Canadian psychology professor,

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[20] LaFountain, 'Health Risk Reporting'.
[21] Paek and Hove, 'Risk Perceptions and Risk Characteristics'.
[22] Anders A F Wahlberg and Lennart Sjoberg, 'Risk Perception and the Media', *Journal of Risk Research* 3, no. 1 (January 2000): 31–50, https://doi.org/10.1080/136698700376699.
[23] Archy O. de Berker et al., 'Computations of Uncertainty Mediate Acute Stress Responses in Humans', *Nature Communications* 7, no. 1 (29 March 2016): 10996, https://doi.org/10.1038/ncomms10996.

has proposed that the unknown is "one of humanity's fundamental fears".[24] Professor Karin Wahl-Jorgensen, who's studied the use of emotions in journalism, observed in February 2020 that the coverage of the outbreak until then had been "characterised by uncertainty, breeding fear and panic".[25]

In my interview with Marie Golimo Kingsrød, a journalist at the daily newspaper *VG*, she said there were newsroom discussions on how to present Long COVID stories without creating too much fear. One strategy they chose was to *emphasise* the individual story, and try not to focus too heavily on numbers and estimates.[26] A large number might grab public attention, but for the reader, a patient's story could be just as memorable – and worrying.

To be clear: fear isn't alway bad. We *should* be scared of catching a new, unknown virus for which we have no natural immunity. Fear of Long COVID can motivate us to learn about and follow advice on social distancing and hygiene. Indeed, studies have shown that more consumption of media (both social and traditional) has been positively correlated with both disease concern, and with preventative measures.[27]

The question is then, *how* scared should we be of Long COVID? As we'll see in the following, that question can be answered in very different ways.

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[24] David Robson, 'Why We're so Terrified of the Unknown', *BBC Worklife*, 26 October 2021, https://www.bbc.com/worklife/article/20211022-why-were-so-terrified-of-the-unknown.
[25] Karin Wahl-Jorgensen, 'Coronavirus: How Media Coverage of Epidemics Often Stokes Fear and Panic', *The Conversation*, 14 February 2020, http://theconversation.com/coronavirus-how-media-coverage-of-epidemics-often-stokes-fear-and-panic-131844.
[26] Marie Golimo Kingsrød, Experiences and reflections after covering Long COVID, phone interview, 5 May 2022.
[27] Chu, Yeo, and Su, 'Effects of Exposure to COVID-19 News and Information'.

Two years, 129 articles

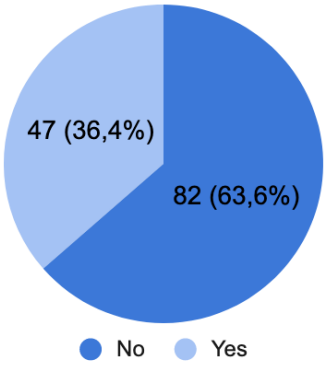
> *"It's horrible. I'm used to having a high intensity job [...]. Now I feel so far from the Ingrid who handles that and loves that. It's tough."*[28]

The quote is from a *VG Pluss* (i.e. paywalled) article from March 2021, in which we meet Ingrid, a 27-year-old Long COVID sufferer. Her story, as told to *VG*, illustrates a few characteristics of Norwegian Long COVID journalism over the past two years.

Between January 2020 and March 2022, the three large Norwegian media outlets *Aftenposten*, *VG* and NRK's online edition published (at least) 129 articles about or mentioning Long COVID. These vary from short news stories about the pandemic where risk of long-term effects is mentioned, to long features and deep-dives. The stories, which I gathered and analysed between March and April 2022, have revealed some interesting patterns in how we've reported on Long COVID:

- More than a third – 36% – of Long COVID articles featured a patient narrative or a "case" (the term used in Norwegian): a meeting with someone who is struggling with long-term effects after being sick (fig 1).

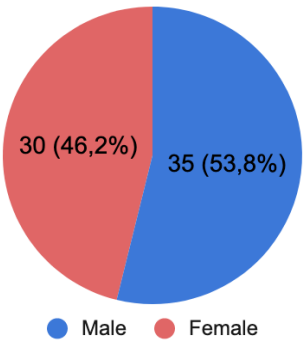
Fig 1: Patient narrative



[28] Louise Krüger, 'Ingrid (27) fikk covid-19: – Jeg er ikke den samme personen', *VG+*, 28 March 2021, https://www.vg.no/i/oAwvLR.

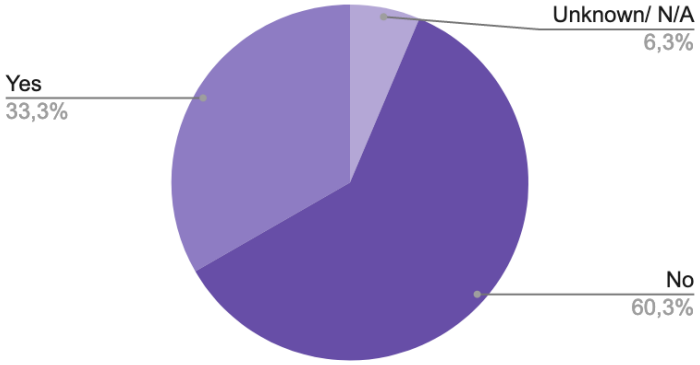
- Long COVID is more commonly reported by women.[29] And yet, 53% of patients featured in Norwegian Long COVID stories were men (fig 2).

Fig 2: Patient gender



- Of the patients featured in these stories, 60% were suffering from Long COVID after having a mild case of COVID – they were never in hospital (fig 3).

Fig 3: Hospitalisation for covid?



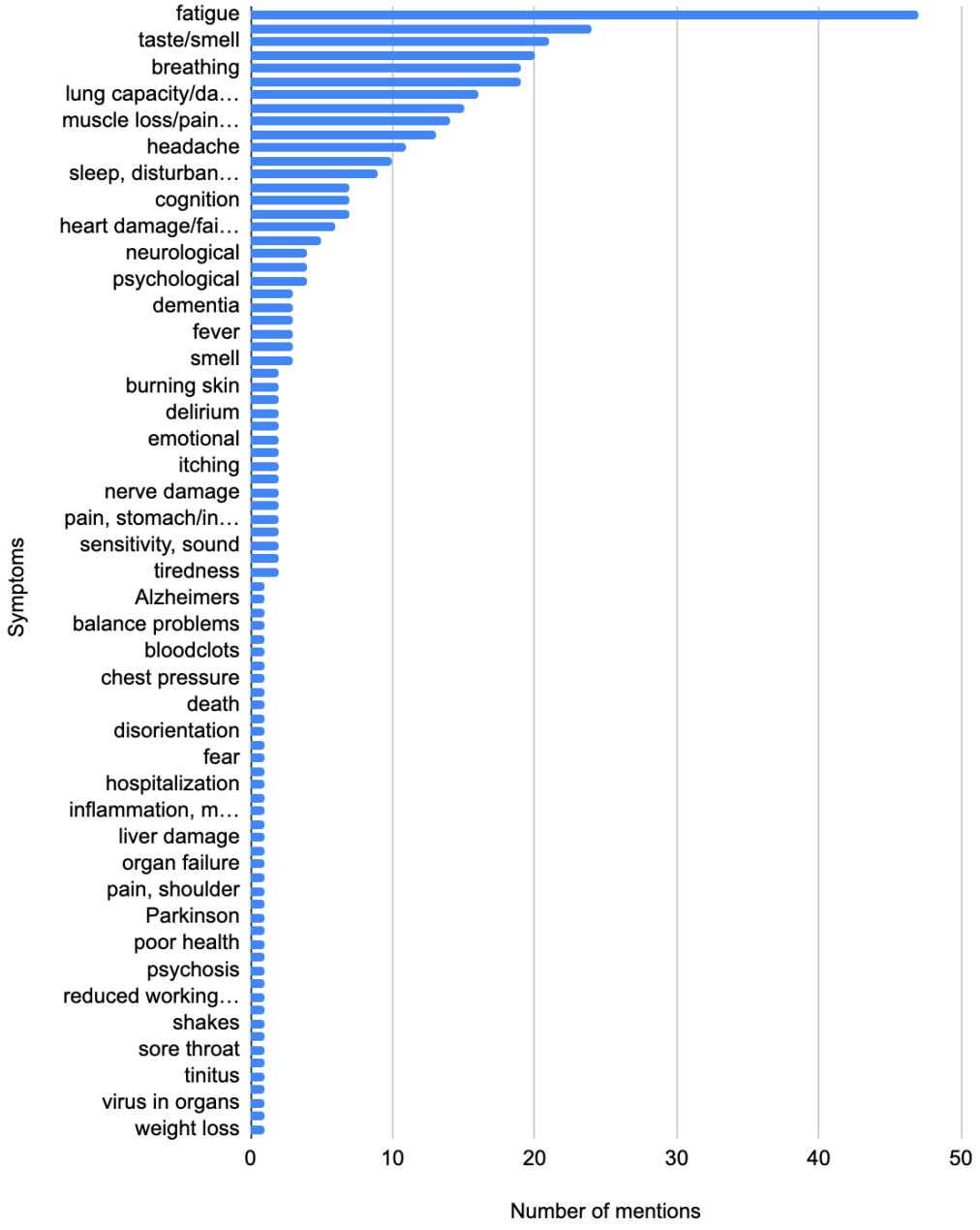
- Stories have included people of all ages, with a slight emphasis on those between 40 and 60 years old.
- Biomedical explanations for Long COVID – like latent virus infection or an overactive immune system – have been mentioned about four times

[29] 'Living with Covid19 – Second Review'.

more frequently than societal or psychological explanations (whether causing or contributing).

- 85 different symptoms have been linked to Long COVID by patients, researchers or other sources (fig 4).

Fig 4: Symptoms



- Only once has a journalist followed up with a patient: the patient was getting married – he had proposed while hospitalised – and *NRK* covered the wedding. Otherwise, we don't know what happened to these patients. Did they get better? Still struggling? As of this writing, the reporting doesn't say.
- The question of long-term damage was first raised early: by both *Aftenposten* and *NRK* before the first national lockdown on March 12, 2020.

"This will be a catastrophe"

I have classified the articles on a five-point scale according to the general tone or mood of the articles: did they highlight the unknown, the dangers, the lack of treatment for Long COVID? Or did the articles mainly focus on a calming message, possible treatment (like rehab facilities) or patients who got better? Some examples of language in "pessimistic" articles are "Nobody knows", "This will be a big problem", ""This will be a catastrophe", "a public health crisis we've barely seen the start of", etc. Articles which included wording like "most get better", "unlikely to be very dangerous" or "not a very big risk", or focusing on possible treatments went into the "optimistic" categories.

Following this – admittedly very subjective – classification, 82 out of the 129 articles were labelled as "pessimistic" or "mildly pessimistic", while only 26 could be seen as "mildly optimistic" or "optimistic".

This mirrors coverage of previous pandemics: a study of the 2006 swine flu found "an overemphasis of threat over protection" in the news coverage, and

the authors concluded that the coverage amplified the public's risk perception.[30]

This isn't surprising, given the media's watchdog function – it might be intrinsically more newsworthy to write about a problem than a solution, and in any case, Long COVID doesn't really have a "solution" to report. But it does support Wahl-Jorgenson's and Hofsø's impression that fear and uncertainty have been key characteristics in the reporting.

Where are the immigrants?

Long COVID sufferers, as portrayed by these three outlets, are white Norwegians. Some articles have featured Long COVID patients from other countries – like patients in the US or Spain – which slightly complicates the picture, but 41 out of the 46 Norwegian Long COVID patients profiled in these articles were ethnic majority Norwegians (as identified by photos and by names like Ingrid, Svein, Åse)

That's 89.1% representation for 83% of the population. Contrast that with the fact that the pandemic has hit the immigrant population of Norway particularly hard. The government-appointed Norwegian Corona Commission concludes that people with immigrant background were almost three times as likely to get infected by the coronavirus and almost four times as likely to end up in hospital.[31] So why aren't journalists talking to them?

In interviews with journalists, this finding has been met with sighs: the underrepresentation of ethnic minority voices in Norwegian media is a

[30] Celine Klemm, Enny Das, and Tilo Hartmann, 'Swine Flu and Hype: A Systematic Review of Media Dramatization of the H1N1 Influenza Pandemic', *Journal of Risk Research* 19, no. 1 (2 January 2016): 1–20, https://doi.org/10.1080/13669877.2014.923029.
[31] Egil Matsen, 'Myndighetenes håndtering av koronapandemien – del 2. Rapport fra Koronakommisjonen', Norsk offentlig utredning, 26 April 2022, https://www.regjeringen.no/contentassets/d0b61f6e1d1b40d1bb92ff9d9b60793d/no/pdfs/nou202220220005000dddpdfs.pdf.

well-known problem (see Shazia Majid's Reuters Institute report on ethnic minority women).[32]

"We're having such a hard time reaching immigrant communities at all. This doesn't surprise me," said Marie Kingsrød from *VG*.[33] The journalists I've interviewed describe it as a structural problem: fewer in immigrant communities read the paper, and so they are less likely to contact the paper if they have a story that ought to be reported. Fewer might think it natural to run an obituary, and so deaths are less visible. And Norwegian journalists have fewer sources in these communities.

The norm: Every "Long COVID sufferer" that was created by the Dall-E algorithm was white. (Image: Dall-E/Boris Dayama et al.)

It is worth noting that some journalists mentioned that when they did try to reach out to non-majority sources, they got help from colleagues with an

[32] Shazia Majid, 'The Invisible: On the Coverage of Ethnic Minority Women in Norway', Fellow's Paper (Reuters Institute for the Study of Journalism, July 2020), https://reutersinstitute.politics.ox.ac.uk/sites/default/files/2021-04/RISJ%20paper_Shazia%20Majid_Final.pdf.

[33] Marie Golimo Kingsrød, Experiences and reflections after covering Long COVID, phone interview, 5 May 2022.

immigrant background.[34] Building relationships and gaining access to under-represented minority communities doesn't happen easily during a crisis. That means the work of avoiding this same under-representation during the next crisis should start now.

Invisible verification

From reading these newspaper articles, it appears journalists rarely probe the stories told by the patients they encounter. Only very rarely do the articles engage explicitly with the patients' narratives, explore them or the patients' health records or backgrounds.

However, in interviews, journalists recount the careful vetting that goes into selecting a "case" for such an article: Dommerud underlined how she never interviews a patient without getting a release, so that she can talk to their doctor without breaking patient-doctor confidentiality.[35] Paal Wergeland, a reporter with NRK, spends a lot of time sifting through stories, e.g. in Long COVID groups on Facebook, and then calling people to find those with histories that are both compelling and documented. "You have to believe people, at least as a starting point. But it's important to be critical when approaching these stories, too. There are people with real problems, and then there are those who just want to whine," he said.[36]

It is rare for journalists to show this part of their reporting: Only two *VG* reporters explicitly mention in writing that they've seen medical records which confirm the diagnosis and medical history. It is worth considering whether including this type of verification work in the final article could help increase the perceived trustworthiness of the reporting – and of the patient's story.

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[34] E.g.: Paal Wergeland, Experiences and reflections after covering Long COVID, phone interview, 6 May 2022.
[35] Dommerud, Experiences and reflections after covering Long COVID.
[36] Wergeland, Experiences and reflections after covering Long COVID.

He said, she said: two Long COVID tales

There aren't many Long COVID researchers in Norway, but those who do study this disease have been interviewed repeatedly by the media. And the roles that they have taken in the public have ended up clearly influencing the coverage.

Arne Søraas is the leader of the Norwegian Corona Study, a large survey which has tracked infections and self-reported health since the summer of 2020. Søraas has been one of the clearest voices of warning in the Norwegian press: the quote at the start of this essay, about how thousands might catch Long COVID, is his.[37]

Søraas was initially not aware of the possibility of Long COVID, he said in our interview – a question about long-term health made it into the survey because a patient representative on their advisory board asked for it. But, when survey respondents started reporting that their health had deteriorated after COVID, Søraas got curious and started digging into the topic.[38]

Kristin Hofsø, on the other hand, is an intensive care nurse and researcher who started looking into Long COVID because she had seen people suffer long-term effects after hospitalisation in previous disease outbreaks: "I expected this very early on", she said.[39] Hofsø has been a calming – and critical – voice in the coverage of Long COVID. "Fatigue after a virus infection isn't uncommon," she told *VG* in March 2021.[40]

[37] Marie Golimo Kingsrød, 'Toppforsker slår alarm om barn og «Long COVID»: – Burde ikke la barn utsettes for dette', *VG*, 28 August 2021, https://www.vg.no/i/oWk3Lm.
[38] Arne Søraas, The coverage of Long COVID in Norwegian media, experiences and reflections, phone interview, 26 April 2022.
[39] Hofsø, The coverage of Long COVID in Norwegian media, experiences and reflections.
[40] Louise Krüger, 'Silje (29): – Jeg unner ingen dette', *VG+*, 26 March 2021, https://www.vg.no/i/9O8bKE.

Another reporter referenced her later that year as saying that "the media's reporting on long-term effects is strongly influenced by scary stories".[41]

How much Long COVID is too much?

These different starting points might explain why the two experts, looking at the same pandemic, tell such different stories. Hofsø thought that a viral lung infection might cause long-term effects for some patients, and so she wasn't shocked or particularly frightened when these started appearing. When interviewed in the media, she has chosen to focus on the majority who *don't* develop Long COVID:

> "I've focused all along on saying that, so far, we don't have any indication that [Long COVID] is more prevalent than what we've seen before. It's just that a lot more people have gotten COVID. The big question is: is this something new, or have we just become more aware of the risk of long-term problems after infection and disease? That's one good thing about the pandemic, it has put this topic on the agenda."[42]

Søraas, on the other hand, was not expecting Long COVID. He was surprised, he said during our interview, by the fact that questions about long-term effects were in the press as early as March 2020 – he and his colleagues had assumed that the topic wasn't on the public's radar when they sent out Corona Study surveys later that summer. (By the time their survey with a question about long-term effects went out, at the end of June 2020, some 15 articles in *Aftenposten*, NRK and *VG* had discussed long-term effects).

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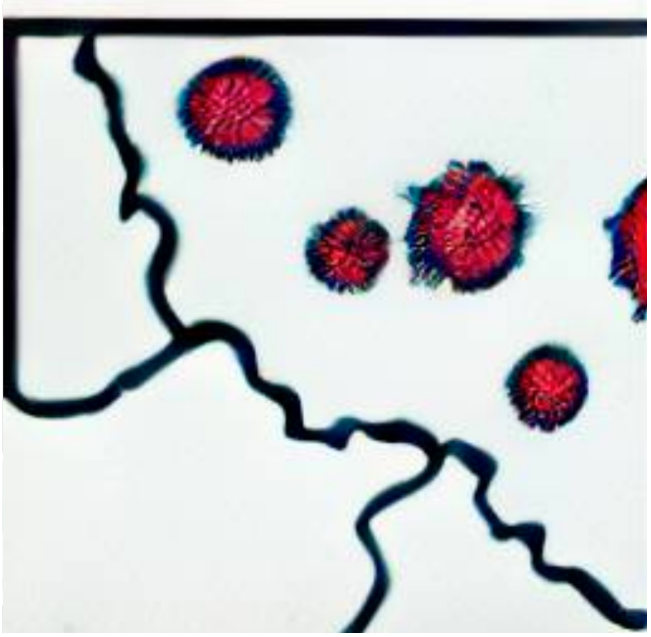
[41] Tine Dommerud, 'Hun lå 64 døgn i respirator. Nå drømmer Anne om morgenbadet i Tønsbergfjorden.', *Aftenposten*, 3 July 2021, https://www.aftenposten.no/norge/i/dl6wLO/hun-laa-64-doegn-i-respirator-naa-droemmer-anne-om-morgenbadet-i-toensbergfjorden.

[42] Hofsø, The coverage of Long COVID in Norwegian media, experiences and reflections.

Another surprise was the type of symptoms: a persistent cough seemed likely, Søraas said, but people were reporting problems like brain fog, which wasn't on his radar.[43]

One could argue that because these researchers had different baselines for what they consider "normal" or "acceptable" levels of post-infection problems, their outlooks were different. (It should be noted that Søraas does not think it has been established that the rate of post-infection problems after COVID is comparable to that of other diseases.)



The virus: The coronavirus SARS-CoV-2, as imagined by the program Dall-E, which creates images from text prompts. (Image: Dall-E/Boris Dayama et al.)

Like Hofsø, Søraas has been mindful about his media appearances and what he's chosen to highlight. It's something he has discussed thoroughly with his collaborators. Søraas sees it as his job to talk publicly about the material they've gathered in The Corona Study, and the uncertainty that exists:

[43] Søraas, The coverage of Long COVID in Norwegian media, experiences and reflections.

> "The idea that most of those who get sick also get well … it's just nonsense, because *we don't know that.* We have no idea what the long-term damages after COVID will be, because it's only been around for two years in Norway. It's obvious to me that we have no idea whether the long-term effects will be terrible or not; it's all speculation."[44]

Kristin Hofsø said she believes her attitude made her less popular as a source – her more cautious comments haven't been as sought after, she said.[45] Søraas was cited twice as often as Hofsø in the news articles I analysed.

Balance is in they eye of the beholder

Neither Hofsø nor Søraas have any issue with the number of Long COVID symptoms that have been reported in the media. A list of 85 separate symptoms might seem long, but it is important to keep an open mind when a new disease emerges, they say.[46] Maybe "itching skin" is something that only affects one out of a thousand patients, Søraas said – but if you don't look for it and report it, you'll never know it was there.[47]

Hofsø brought up the paradox LaFountain wrote about during our interview: why did the media focus so heavily on the "mysterious illness" (Long COVID) and less on the risk of winding up in hospital with COVID-19, with all the long-term complications that that can entail?

> "Everything points to there being a connection between the severity of your case of COVID, and your risk of Long COVID. It's not like you'll be on the subway, a virus will fly by and suddenly you get Long COVID. That's extremely rare. There are some very few cases, of course – this

[44] Søraas.
[45] Hofsø, The coverage of Long COVID in Norwegian media, experiences and reflections.
[46] Hofsø.
[47] Søraas, The coverage of Long COVID in Norwegian media, experiences and reflections.

> world is full of exceptions. But those rare occasions have gotten a lot of attention and created so much fear."

Hofsø said she doesn't blame the media for what the coverage has been like – scientists have contributed to the mood, she said, because of a wish to be the first to report a new phenomenon. And the first assumptions about Long COVID *were* helpful in an uncertain situation: you have to start somewhere. But the persistent focus on fear and threat is a problem, she said: "Walking around being scared isn't good. You start looking for things that confirm your fears."[48]

Søraas, on the other hand, said he has found the media coverage of this phenomenon quite balanced: "Given that it's a new phenomenon, I've found it rather sensible. They've tried not to exaggerate the danger, but at the same time you maybe shouldn't *underplay* it either." He is more critical of those in the medical community who have tried toning down Long COVID. Søraas recounts how he has twice been called by higher-ups at the Oslo University Hospital and told he was "scaring people" after a media interview. "It's a touchy subject," he said.[49]

Journalists in the middle

When medical experts have such different views, it becomes hugely challenging for journalists to cover a topic like Long COVID: to whom do you listen? Who do you call for a comment or explanation? The coverage in Norwegian media has, to some extent, followed the scientific literature. There has been an uptick in the number of articles on Long COVID after new numbers have been published, and especially when studies based on Norwegian data have come out. But it seems scientific debates have seeped into newsrooms as well.

[48] Hofsø, The coverage of Long COVID in Norwegian media, experiences and reflections.
[49] Søraas, The coverage of Long COVID in Norwegian media, experiences and reflections.

I interviewed one journalist from each of the three newsrooms whose work I analysed, and the conversations reflected the two perspectives that Hofsø and Søraas raised.

Paal Wergeland from NRK, for example, said his journalistic efforts had been mainly focused on those who *do* develop Long COVID – and argued that they are the ones who deserve our attention. "The starting point has to be that this is something that many people say they struggle with. That's maybe something you should acknowledge journalistically, and not balance 100% [by including someone downplaying the risk of Long COVID.]"[50]

Others wanted to focus more on the majority who *don't* develop COVID, and a desire not to scare them unnecessarily. "I have the utmost respect for the fact that many become really sick, and I've interviewed people who've been really sick. But I also have respect for the idea of a self-fulfilling prophecy – so we think carefully about this coverage," said Tine Dommerud, the *Aftenposten* health reporter.[51]

It is interesting that these perspectives mirror who the journalists met first in their work on this topic: Wergeland had his first introduction to Long COVID through an interview with Arne Søraas, whereas Dommerud and Marie Golimo Kingsrød from *VG* first talked about this phenomenon with other researchers who've been more focused on the risk of creating fear. Kingsrød was even warned by a researcher, early on in the pandemic: "The more you write about Long COVID, the more Long COVID there will be."[52]

When reporting on Long COVID started, nobody knew that the scientific community would develop these opposing viewpoints. The disease was new and unknown, the borders not yet delineated. But the split has now become clear.

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[50] Wergeland, Experiences and reflections after covering Long COVID.
[51] Dommerud, Experiences and reflections after covering Long COVID.
[52] Kingsrød, Experiences and reflections after covering Long COVID.

As Wergeland said: "You can always find an expert to suit the angle you want."[53] So how to navigate and present these different perspectives?

The main tools, my interviewees said, are the basic ones: Knowledge, and multiple sources. All of them have been part, for longer or shorter periods, of "COVID groups" in their newsrooms, teams dedicated to covering the pandemic. That was important: "For me it's easy to call this or that researcher – I know who they are and where they're coming from; I know if they should also be balanced with other sources," said Dommerud.[54] It's much harder to keep track of scientific debates for journalists doing shifts in the newsroom, covering anything and everything that comes up.

Different viewpoints should come out in the article, my interviewees agree, but that means you have to know that there *are* different viewpoints. That requires at least some degree of specialisation.

Although many articles published by these outlets have included interviews with multiple sources, you still have to be an attentive reader to catch this ongoing debate among Long COVID researchers: only three out of 23 articles where Long COVID researchers have been interviewed have included more than one. A single article, in *Aftenposten*, explicitly covered the ongoing scientific debate about how to understand Long COVID.[55] The differing viewpoints become clear if you follow the coverage closely and over time, but it is hard to say if they would come across for a casual reader. Speaking from experience, it can be hard for journalists to remember that not everyone inhales the news like we do. Do we leave too much up to the public when these differing viewpoints aren't made explicit?

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[53] Wergeland, Experiences and reflections after covering Long COVID.
[54] Dommerud, Experiences and reflections after covering Long COVID.
[55] Ingeborg Moe, 'Sverige har egne mottak for dem som sliter etter korona. Legen er selv en av pasientene.', *Aftenposten*, 10 May 2021, https://www.aftenposten.no/verden/i/dlEV5z/sverige-har-egne-mottak-for-dem-som-sliter-etter-korona-legen-er-selv-en-av-pasientene.

Can you question lived experience?

In July 2020, *VG* interviewed a Swedish woman, Åsa Hedlund. She had been sick with COVID some months back, but she was still struggling. Hedlund listed a lot of different symptoms: fever, chest pain, a stomach ache, burning skin, racing heart, shakes, back pain, swelling, diarrhoea. She had problems getting enough oxygen and problems concentrating.[56]

Hedlund's story came to mind during my interview with Marie Kingsrød from *VG*. Kingsrød was talking about an uncomfortable voice in the back of her head when she first started reading reports about Long COVID in international media: "Is it real? I mean, you don't want to think that, but is it all in their heads?"[57]

Long COVID is a disease without a clearly defined list of symptoms, or an easy explanation. It's hard to predict who might get it, and the patient might not have external "proof" that the coronavirus was in fact the origin of their problems. After all, just because something happened *before* your problem started, it does not mean it *caused* your problem. To be clear, neither Kingsrød nor any of the journalists or researchers I've interviewed have indicated that they don't believe Long COVID is real. But a journalist should seek the truth and verify claims. So can you question a patient's lived experience in the way that you can – and should – probe statements from doctors, politicians or researchers? How do you go about seeking verification on a couch in Hedlund's living room, while also listening to what her life has been like while ill?

In short: How do you balance an *empathetic presence* with the need for *journalistic verification*?

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[56] Natalia Kazmierska and Jørn E. Kaalstad, 'Åsa har hatt feber i over 100 dager – var coronasmittet', *VG*, 2 July 2020, https://www.vg.no/i/OpwpdE.
[57] Kingsrød, Experiences and reflections after covering Long COVID.

The ghost of the chronic fatigue debate

The backdrop for this discussion – and for my interest in the coverage of Long COVID – is the ghost of chronic fatigue syndrome (CFS), or ME. CFS is another contested illness, with patients suffering often-unexplained but persistent and sometimes debilitating symptoms. These patients have been met with disbelief from some doctors and no good answers from scientists. It has led to a lot of acrimony, and both researchers and journalists now say they shy away from working or reporting on CFS.[58]

At the moment, Long COVID seems to be more accepted as "something real" by the public and by doctors. But there is a risk that the same dynamics that made CFS such a fraught topic could start to play out with Long COVID. There are warning signs in the U.S.: in a few high-profile examples, patient activists have become furious about the presentation of the disease in articles, and magazines such as *The Atlantic* have featured long discussions about the "need to believe long haulers".[59,60]

Tine Dommerud, the *Aftenposten* journalist, admitted that this worries her. In one instance, a Long COVID patient she interviewed became very upset about the article when it came out, because a photo presented her as "sicker" than she herself wanted to be seen. "I wonder if she worried that people around her would see her continued symptoms as a weakness. Even though she had been really sick – she was on a respirator."[61]

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[58] Fiona Fox, 'First They Came for the Communists: The Bitter Row over ME/CFS Research', in *Beyond the Hype: The inside Story on Science'smiggest Media Controversies* (London: Elliott & Thompson, 2022).
[59] Dhruv Khullar, 'The Struggle to Define Long COVID', *The New Yorker*, 20 September 2021, https://www.newyorker.com/magazine/2021/09/27/the-struggle-to-define-long-covid.
[60] Ed Yong, 'Long-Haulers Are Fighting for Their Future', *The Atlantic*, 1 September 2021, https://www.theatlantic.com/science/archive/2021/09/covid-19-long-haulers-pandemic-future/619941/.
[61] Dommerud, Experiences and reflections after covering Long COVID.

We should be prepared, she said, that some of the dynamics from the CFS debate might come into play in the continued media debate about Long COVID.

How *not* to question lived experience

The Long COVID researchers, Hofsø and Søraas, both demurred when asked about the idea of journalists probing patients' stories. Yes, they both say – it *should* be possible for journalists to ask questions to verify patients' stories and to try to substantiate them with documentation or data.

"Ideally, it would be good to ask those kinds of questions, but I can see that in an interview situation, you have to be careful going 'but, do you think this all stems just from COVID?'," said Hofsø.[62] Søraas agreed: delving into a patient's story is what a good doctor does in order to provide the right help, and should be a part of what a journalist does, too. But, "it could be difficult". [63]

As journalists have recounted in my interviews, and as I've experienced myself, there are many ways of getting this sort of probing wrong:

- Some journalists have asked questions during the interview which were seen by the patient as a sign that they weren't being believed – and the conversation froze.
- Some have had patients withdraw their interview because of follow-up questions after the interview. A journalist might ask for details about some facet of the patient's history in order to make the article more vivid, but this can – and has – been seen as digging to find holes in the story.
- Some have done everything "right" during and after the interview: the patient got to read and approve their quotes (a common practice in

[62] Hofsø, The coverage of Long COVID in Norwegian media, experiences and reflections.
[63] Søraas, The coverage of Long COVID in Norwegian media, experiences and reflections.

Norwegian journalism), were told the context, what other kinds of sources would appear and they got to see the pictures. But still, they were devastated when the article ran because an expert was quoted elsewhere in it, saying something that the patient saw as a critique of them and their story.

Reducing the patient-expert divide

When this part of the journalistic process becomes fraught, I believe a core issue is the way we frame patient narratives, or "cases". Too often patients are cast as "the humanising angle" – there to fill a specific, experiential role.

This is reflected in research on the use of patient narratives – or exemplars, as they're often called in the scientific literature. A few years ago, a group of American researchers interviewed journalists about this topic, and concluded that "journalists select exemplars to serve the purposes of *informing*, *connecting*, and *getting attention*." But, they continue, journalists believe patients are less important for "aiding audience understanding", compared with experts, data and statistics.[64]

It is worth asking whether this attitude can and should be challenged. Could this divide between "patient" and "expert" be diminished? Giving the patient an active role in the article, presenting them as someone the other sources talk *with,* is different from having them be the object that politicians and researchers talk *about*. That means fully integrating them and their perspectives in the discussion.

This was also the conclusion of Julie Rehmeyer, a freelance journalist who herself suffers from chronic fatigue syndrome. In an opinion piece about

[64] Amanda Hinnant, María E. Len-Ríos, and Rachel Young, 'Journalistic Use of Exemplars to Humanize Health News', *Journalism Studies* 14, no. 4 (1 August 2013): 539–54, https://doi.org/10.1080/1461670X.2012.721633.

reporting on contested illnesses, one of her main pieces of advice is to treat the patient as an expert: "Patients are the only people who can observe an illness from the inside, so they offer critical expertise."[65] But, Rehmeyer cautions, like all experts, these patients aren't all the same. Some have theories, some don't, some have researched their condition to death, others haven't. Many different types of patients can be good sources, but you need to choose carefully – like any other source.

There are multiple strategies that a journalist can use while working on a story to try to reduce the patients-expert divide:

Preparing the interviewee

This came up again and again in interviews for this essay: journalists spoke to the patient before an interview to give them a heads up: "I will be asking you some questions that you might find difficult – but it's better that I ask now than that the reader is left wondering."[66] I contend that these "difficult questions" ought to be included explicitly in the article more often. If the patient got a challenging question about their history or condition, and answered it interestingly and convincingly, then the reader should have the opportunity to see and experience that moment too.

Letting them explain

Don't ask "Are you sure your problems were caused by COVID?", but rather "*Why* do you think your problems were caused by COVID?" Again, it means giving the patient the chance to shine, and to preempt any doubts the reader might have.

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[65] Julie Rehmeyer, 'How to Report with Accuracy and Sensitivity on Contested Illnesses', The Open Notebook, 26 January 2021, https://www.theopennotebook.com/2021/01/26/how-to-report-with-accuracy-and-sensitivity-on-contested-illnesses/.

[66] Dommerud, Experiences and reflections after covering Long COVID.

Right of reply

If the news article is going to feature sources with differing views – say, not just a patient who believes Long COVID is a purely somatic illness, but also someone who believes the disease is influenced by psychological stressors – then give the patient an opportunity to respond to the opposing view. This does not mean forcing patients to argue about scientific papers, but letting them have a chance to react and reflect on the idea that the disease can be affected by stress, speaking from *their* lived expertise. It is what we do when experts disagree and, done carefully, we can bring patients into that conversation. Additionally, a commitment to letting patients respond could give journalists a chance to uncover and talk about any difficulties that the patient might be having about the framing of the article – before it becomes a problem.

Conclusion

During the first two years of the coronavirus pandemic, Long COVID changed from being a scary possibility to a real phenomenon – and a real challenge for journalists.

The carer: How should journalists meet Long COVID patients with undocumented stories? Dall-E's imaginings of a "Long COVID sufferer". (Image: Dall-E/Boris Dayama et al.)

The jury is still out on almost every question: how prevalent is Long COVID, and why does it affect people in such different ways? What degree of long-term effects are to be expected, and how much is too much? Why aren't doctors finding clear causes for the problems that Long COVID sufferers are reporting?

Navigating tensions between different experts – and between experts and other types of sources – will be a challenge for journalists for years to come. This supports the idea that journalists should have some degree of specialisation: you can't make deliberate choices about sourcing and framing of disputes if you're not aware that the dispute exists.

We should also broaden our network of sources to make sure that we can report on how crises such as a pandemic affect marginalised communities. We should make more of our work and our journalistic choices transparent and visible to readers. And we should try to be deliberate in our use of patient narratives, making sure that we include patients not just as humanising examples, but as experts in their own right.

These suggestions won't resolve all tensions that arise when reporting on contested illnesses; there will still be disputes about reporting on Long COVID, and still instances where journalists' questions or researchers' statements will clash with patients' need to be heard and understood. That might be unavoidable but, as we've learned from the CFS debate, leaving them unacknowledged does no one any favours.

With contested illnesses like Long COVID, there is an inherent tension between the journalistic need for empathetic listening and verification. The point is not to resolve the tension, but to face it head on.