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Adapt and Adjust: Doing UK-Based Ethnographic Fieldwork During the Covid-19 Pandemic

Lucy Johnson

Department of Anthropology, Durham University, Durham, UK

ABSTRACT

The Covid-19 pandemic has required many anthropologists to do fieldwork differently: research that would otherwise have been done face-to-face has been shifted online, sometimes very quickly. When doing research with people with chronic illnesses, it is important to acknowledge both the histories of online ethnography and the way that disability studies has engaged with the internet over time. This article uses the example of my PhD fieldwork, based in Northeast England, to explore how living in an increasingly digital world may impact how medical anthropologists could, and perhaps should, do ethnography.

KEYWORDS

Chronic illness; chronic pain; disability anthropology; health inequalities; North East England; online ethnography

In November 2020, UKRI (UK Research and Innovation, the main UK Government research funder), the funder of a large proportion of UK doctoral students, released a policy statement detailing their position on disruption to doctoral degrees caused by the COVID-19 pandemic. In light of “limited resources” to provide funded extensions for students affected by the pandemic, UKRI advised those unable to carry out in-person research activities during periods of restrictions to “adapt and adjust research projects” to “ensure they can complete it within their funded period” (UK Research and Innovation 2020:1). Students were advised to do this by changing their “research question, approach, or methodology” (UK Research and Innovation 2020:1). Within this statement are expectations about what “normal” research is (offline, best, normal) and what “adapted” research is (virtual, adjusted). It provides an example of some of the epistemic and methodological consequences that the Covid-19 pandemic has had on how research is carried out.

In this article I reflect on the assumptions embedded in the UKRI policy statement, and use the example of my doctoral fieldwork to argue that wholly online research, or research using elements of online methods, should not just be regarded as a back-up plan when traditional face to face research is impossible. My doctoral research focuses on the relations between people who live with chronic pain in North-East England, and the opioid pain medications they use. The aim of my doctorate is to explore how the nexus of chronic pain and opioid prescriptions in the North East are emblematic of the worsening health inequalities in England (Corris et al. 2020; Marmot 2020), as evidence suggests that the landscape of pain and opioid prescriptions in the North East is influenced heavily by socio-economic deprivation (Curtis et al. 2019). I use my experiences as an example, and address how the consequences of the COVID-19 pandemic changed my research methodology, requiring me to do research that was radically different to what I had planned.

As the pandemic has become interlaced with existing health inequalities and geographical patterns of disability (Bambra et al. 2020), I have needed to consider my own positionality, and furthermore how the methods used during my fieldwork have been impacted by COVID-19. Part of this has

CONTACT Lucy Johnson  Lucy.l.johnson@durham.ac.uk  Department of Anthropology, Durham University, South Rd, Durham DH1 3LE, UK

Media Teaser: what could medical anthropologists learn methodologically from doing ethnographic fieldwork during a pandemic?

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involved taking a “pain centric model of disability” – in other words taking the position that living with chronic pain, regardless of diagnosis or physical cause, is disabling (Jones 2016). My research now takes an interdisciplinary approach, incorporating approaches from medical anthropology and disability studies to follow Hartblay (2020)’s definition of disability anthropology. As the pandemic has progressed, I have learned the importance of incorporating this “disability anthropology” approach deeply into my research designs and methodologies. To do this, I have used literature and perspectives from disability studies, alongside medical anthropology, to ensure that the experiences of disabled people both prior to, and during the pandemic, are central to my methodology (Hartblay 2020:27).

Here, I provide an overview of online ethnography, situated alongside a discussion of how disabled scholars and activists have used the Internet to do research (and make the kinds of adjustments made mainstream by COVID-19) in the years leading up to the COVID-19 pandemic. These histories, while having significant overlap, are not identical. In coming years, medical anthropologists will need to think carefully about how to do research in a world where digital technologies and humans live increasingly entangled lives. After all, COVID-19 has influenced, and perhaps amplified, our engagements with digital worlds, but it did not create them. Throughout this article I want to emphasize how using approaches which encompass online research methodologies and draw from disability studies has the potential to produce health research which more holistically understands the lives of the participants and interlocutors who take part in our research. Broadly speaking, I consider how the use of online methods, and the lessons learned from doing research during a pandemic, could benefit medical anthropologists in future years. But, this must come alongside an awareness of the many ethical dilemmas, and possibilities, doing research this way could pose.

To illustrate this, I outline the practical changes made to my research design to allow me to continue doing research with chronically ill people, during a pandemic. Using ethnographic examples from my fieldwork, I illustrate how doing “pandemic fieldwork” can facilitate three different kinds of access; to people, space and time. These different forms of access, and their intersections, demonstrate the benefits of incorporating approaches from online ethnography and disability studies into research methodologies. Furthermore, I also discuss the epistemic and ethical consequences that doing this research has had for me individually, and consider how this could inform how medical anthropologists do research in the future.

Online ethnography and disability studies

Situating online ethnography

Online ethnography has a specific methodological lineage within the social sciences (Burrell 2009). Studying online phenomena can be considered in tandem with the move in anthropology away from the traditional “bounded” field site, toward multi-sited ethnographies and “non-places” (Marcus 1995). From the early 1990s, anthropologists have been increasingly intrigued by the possibilities the Internet has to shape the world and create new ethnographic field sites (Escobar 1995; Escobar et al. 1994). These concepts are primarily focused on the relationships that form between people and information technologies, and the material role these technologies play in social lives (Miller 2018).

Early literature on the anthropology of the Internet anticipated the forms that the “anthropology of the future” might take. Hables Gray and Driscoll (1992) imagined a dystopic “cyberspace” shaped by a masculine military imaginary. However, the present-day realization of this space is a slightly different dystopia to that imagined in the 1990s. “Big data” produced by the banal, everyday interactions human beings have with the Internet has created a “new, and even more efficient, panopticon” (Han 2017:8). Rather than the creation of cyborgs, it is interactions between people, mediated by Information Technologies, that has formed this “anthropology of the future.”

The mass uptake and use of participatory “Web 2.0” platforms such as Facebook, WhatsApp, Twitter and Instagram produces a large amount of this big data. Prior to the year 2000, the Internet consisted mostly of “Web 1.0” sites, with unmodifiable content; visitors to these websites were not able

to participate in the creation of content. By contrast, Web 2.0 platforms, which gained popularity after the millennium, have functionality which allows people to create their own content and communicate with each other (O'Reilly 2005). Hine (2015) argues that, although useful, the distinctions between Web 1.0 and 2.0 platforms do not fully capture what is interesting about the Internet to ethnographers. It is the ability, or potential, for participation which has shifted the Internet to its position today as a “cultural object” (Hine 2015:13). For many, the Internet can be an extension of offline lives and communication networks (Boellstorff et al. 2013). Anthropologists of the Internet have successfully used these participatory platforms to interact with potential research participants. By doing so they have been able to understand more about how lives are lived online, and how the technologies that facilitate online lives are embedded in the wider social context (Miller 2018).

The internet and health

Within the social sciences, online methods have produced some excellent research on how the Internet shapes the experience and understanding of health and illness (For examples see: Gillett 2003; Gonzalez-Polledo 2016; Gonzalez-Polledo and Tarr 2016; Lowe et al. 2009; Marcus and Singer 2017; Nettleton et al. 2005; van Uden-Kraan et al. 2008). The use of online methods to understand health and wellbeing has been used extensively by social scientists in the past to analyze how and why the Internet is important for health. This kind of research focuses on how the Internet is used by people with different health conditions to find information, interact with others with similar conditions and create new meanings around illnesses.

Specifically within medical anthropology, these approaches have been used to research previous infectious disease outbreaks. For example, Marcus and Singer (2017:342) analyzed the Internet memes produced during the 2015 Ebola outbreak in West Africa, exploring the “biosocial experience of an infectious disease epidemic in the age of the Internet.” By analyzing Internet artifacts, they demonstrated how the Internet can be used effectively to understand aspects of an acute health crisis – the use of online methods to research epidemics and pandemics did not begin with COVID-19. However, the research undertaken by Marcus and Singer (2017) was designed to be online and to focus on the digital artifacts that were created during the Ebola epidemic. The contrasts with much of the research that has taken place during COVID-19, which has occurred in digital spaces through necessity rather than by design.

Disability studies and the Internet

When considering how the Internet has been used to study health, we need to consider how disability studies and activist movements have approached the Internet prior to, and during, the pandemic. “Digital Activism” can be hard to define (Kaun and Uldam 2018), but its origins can be broadly traced back to the use of social media during the “occupy” and the “decolonize disability” movements in the US during the early 2010s to produce new, internet mediated, methods of protest (Block et al. 2016). The Internet has long been used by disabled scholars and activists to produce research, and to create and maintain activist communities.

The specific convergence of disability studies and the Internet is not new, and has existed in tandem with increasing interest in the Internet as an ethnographic research site. Understanding this convergence is key to thinking about how ethnography has been used to produce insights into the experience of disability in the past, and could be used effectively by medical anthropologists in the future. A prominent example of the interactions between online ethnography and disability studies is Boellstorff (2008)'s ethnography *Coming of Age in Second Life: an Anthropologist Explores the Virtually Human* and subsequent articles (Boellstorff 2020; Boellstorff et al. 2013). Other examples, often from within (or drawing from) critical disability studies, have emphasized the importance of the Internet for disabled people both in terms of providing specific accessibility, but also in terms of the epistemic consequences carrying out research online can have (See: Burke and Crow 2016; Davis and Boellstorff 2016; Ginsburg 2012; Hartblay 2019).

The history of disability studies' involvement with the Internet logically links up in many places with the history of online ethnography. However, it is important to remember that, for two decades now, disabled people have been enacting social lives, doing activism and undertaking research online in the kinds of ways seen more broadly during the pandemic. This raises questions about whether the pandemic has really changed the way social lives are lived online, or whether the possibilities for exploring social interaction using online methods have simply broadened and become more visible to researchers. In the rest of this article, I will discuss how the pandemic forced a change in my own research design and subsequently had important consequences for the kind of data I collected. Throughout, I emphasize that this change in research design, and the ensuing experiences I had doing fieldwork, have created an epistemological and methodological position for me which should have already existed. The COVID-19 pandemic forced a flexibility into my research design which should have been there by default, and will need to be present for any research I undertake in the future.

March 2020: a shift in research design

I started my PhD in October 2019, and for the first few months was busy planning my “offline fieldwork,” although at this point I just considered these plans my “fieldwork plans.” In March 2020, amid legal restrictions on social interaction due to the spread of SARS-CoV-2 in the UK, my planned fieldwork was suspended. Many aspects of my original, offline, research design became impossible. Like many other doctoral students and early career researchers (and certainly not only those funded by the UKRI), I had to radically reevaluate my fieldwork plans to allow me to obtain ethnographic material under a vastly different set of parameters and complete my research within the required period. When planning my research, I needed to build in multiple research plans which would allow me to complete my research entirely online, entirely offline, or a mix of both as COVID restrictions allowed.

To do this, I had to plan firstly to move all of my recruitment online to ensure compliance with UK COVID guidelines. I contacted all participants using the Internet,¹ rather than from a GP surgery or community center as originally intended. In the majority of cases,² I first obtained the e-mail of interested potential participants via Facebook, and sent them an e-mail from my university e-mail address detailing a bit about myself, and attaching my research information sheet. If the potential participant was interested, they would get back in touch with me over e-mail and we would arrange a Zoom call, using my university-affiliated Zoom account. The use of university affiliated software allowed me to demonstrate to my participants that my research was legitimate and that I was a “real person”, before we had even arranged a video call. These video calls were mediated by smartphones, laptops or tablets, depending on the equipment available to the participants.

The participants who took part in my research were all white women, with ages ranging from 23–70 years. Alongside age, the educational level of participants varied widely; some had left school at 16, and others had postgraduate degrees. The homogeneity in ethnicity and gender is likely due to the demographic makeup of the UK's North East; census data from 2011 suggests that North East England has the highest White British population (93.6%) in the United Kingdom (Office for National Statistics 2012). Similarly, conditions like fibromyalgia – which affect many people who took part in my research – are disproportionately diagnosed in women (Creed 2020).

Once we had spoken over Zoom, discussed consent, and got to know each other, I asked whether the participant would be comfortable giving me their phone number so we could keep in touch more easily. We would then chat over WhatsApp whilst simultaneously continuing to arrange “interviews” over Zoom periodically. The first few of these “interviews” were often (with consent) recorded as they entailed the quite detailed “life histories” or “illness narratives” of my participants. These recorded interviews were stored using the same procedures as for “offline” interview recordings, in line with University Research Governance guidelines. After these interviews had taken place, I often continued

to arrange Zoom calls with participants as and when they had the time, where we would “hang out” online together and chat.³ As I got deeper into my fieldwork, the use of Zoom became quite habitual, as it was a medium both research participants and I felt familiar and comfortable with.

By the time I got to meet any participants face-to-face, I had often known them for several months already. The intimacy which we had often built up by chatting over Zoom and Whatsapp completely changed not only how I did my research, but what I researched too. The changes I had to make to do my fieldwork have caused me to reflect on what it means to do research that jumps between, and straddles the boundaries of, online and offline worlds. Using ethnographic examples from the periods of COVID-19 restrictions in the UK (June 2020-June 2021), in the remainder of this article I consider how doing this strange fieldwork, which was dictated by the boundaries discussed above, created different “kinds” of access – across and between people, space and time.

Three types of access

Access to different people

As I sat in my home office in the early months of pandemic restrictions, I thought long and hard about what the impact of COVID-19 on my research would be. Doing ethnographic fieldwork focused on chronic health issues during an acute health crisis has presented many challenges, the first of these being access to research participants. As time passed, and the initial shock of the pandemic began to fade, research which focused on COVID-19 and health inequalities began to emerge. This kind of research helped me to theorize how the impact of the pandemic would shape the form my research would take, practically.

Covid-19 has been described as a “syndemic pandemic” (Bambra et al. 2020). The idea of the “syndemic” emerged from research done at the intersection of public health and medical anthropology, and describes the interaction between two or more “afflictions” during an infectious disease outbreak (Singer and Clair 2003). Bambra et al. (2020) demonstrated how this has manifested as COVID-19 has become established in communities in the UK, showing how rates of mortality and serious disease from the SARS-CoV-2 virus relate to existing patterns of health and geographical inequality. Furthermore, the authors found that the patterning in morbidity and mortality rates from COVID-19 are comparable to those seen during the 1918 Spanish Flu Pandemic, demonstrating the historic entrenchment of these inequalities.

As noted in the introduction, the issue addressed in my PhD fieldwork is therefore fundamentally related to health inequality. Any face-to-face research with people living with chronic pain in North East England had (and still has) the potential to put groups already at disproportionate risk of harm from COVID-19 at further risk. The necessity of the shift to online fieldwork, mandated by university ethics boards, was required to ensure safety of both researchers and participants. However, recruiting research participants entirely online created a complex set of limitations, some of which presented, and continue to present, a challenge to the very foundations of my research. Some of the decisions I made may, in turn, serve to perpetuate the very inequalities I want to explore as part of my research.

This is because the inequalities exacerbated by COVID-19 are not just limited to health. The pandemic has also highlighted enormous inequities in Internet access, both in the UK and globally (Majeed et al. 2020; Watts 2020). These concerns regarding digital exclusion are not new. (Office for National Statistics 2019) has shown that that UK has a persistent “digital divide” which hinges along axes such as age, ethnicity, socio-economic status and disability. However, digital and health inequalities do not exist in isolation from each other. The ability (or lack thereof) to access the Internet has had a marked impact on an individual’s ability to access digital/remote healthcare during the pandemic, or to be able to download and utilize the “NHS COVID-19” application (Watts 2020). During the pandemic, the importance of the Internet has become ever more significant, not only to allow people to work and socialize, but also to allow access to healthcare.

This issue of digital inequality is therefore central when researching health inequalities during a pandemic (and beyond). For my own research, knowledge of this is especially pertinent. North East England has the highest proportion nationally of non-Internet users: 12.1%, of which disabled adults make up a disproportionate share (Office for National Statistics 2019). We might expect, therefore, that people who use prescription opioids to treat chronic pain may be disproportionately excluded from Internet access, or lack the “digital capital” (Hampshire et al. 2015:98) that would allow them to participate in online research (or indeed, access online healthcare) with ease. Doing online fieldwork on chronic pain and prescription opioids in North East England therefore raises significant questions about representation and exclusion. Who is not being represented when research is pushed online through necessity, rather than design? Do we risk systematically excluding people whose experiences are crucial to understanding the mechanisms of social inequality and exclusion? Even with an understanding of how disability studies has historically used the Internet to produce research and create activist spaces, these questions are still necessary to raise as we look to the future.

Recruiting participants using online methods was essential, but may have resulted in the exclusion of many potential participants without good Internet access or digital skills. However, I found that online recruitment opened up ways of reaching other participants who I might not otherwise have encountered. This type of access to people was unplanned, but adds layers of complexity to the issues discussed above. As previously discussed, participants were recruited from North-East based, chronic pain-specific Facebook pages. Importantly, these pages are created, moderated, and populated by people who live with chronic pain. The emancipatory possibilities of online spaces for people who live with disability and chronic illnesses have been discussed, both in terms of social media (Gonzalez-Polledo 2016) and online gaming (Boellstorff et al. 2013). The Facebook groups I recruited participants from provide a private (and entirely online) space for people who live with chronic pain to discuss their experiences, detached from any official clinical space.

In February 2021, I was chatting over Zoom with Hannah, a woman in her 20s who had been diagnosed a few years earlier with fibromyalgia, a painful chronic illness with (as yet) no known cause. Hannah had messaged me on Facebook, giving me her e-mail address so I could send across more information about my research and saying she was keen to talk to me about her experiences. She has regular chronic pain “flare ups” and often ends up attending her local Accident and Emergency department to receive urgent pain relief. Over the course of this Zoom call, she explained to me that due to some of the things she has experienced when seeking pain relief in acute care, she has a fear of doctors.

We were talking about how my research was going, and about how stressful and strange the last year had felt. I told her about how I had had to change my research plans to work online and recruit via Facebook. As mentioned earlier, originally, I had wanted to apply for National Health Service (NHS) ethics and recruit from within General Practice (GP) clinics. I expressed to Hannah how I was grateful to be talking to her as I had been worried about not finding anyone to help me with my research. After I said this, Hannah paused for a few seconds. I watched her burst out laughing from the other side of the screen. After she’d finished laughing, she explained to me that “there is NO way I’d have wanted to take part in this project if you had approached me at my GP surgery!” She went on to reiterate the fear she feels around attending her GP clinic, and how the negative experiences she has had previously would have made her wary about talking about pain and opioid use with anyone associated with the NHS. For me to be separate from an official body like the NHS (despite being clearly associated with my academic institution) was important for her and made her feel like she could talk to me without judgment.

The interaction I had with Hannah demonstrates that by approaching these community-led Facebook groups using the kind of methods already used and understood by online ethnographers (Gonzalez-Polledo 2016; Hine 2015), and adopting research principles advocated for by disability scholars (Boellstorff et al. 2013; Burke and Crow 2016), I had inadvertently addressed a power imbalance I had overlooked in my original research design. The issue of digital and health inequality

means that online research can be exclusive. However, by being mindful of the benefits recruiting participants online can bring, medical anthropologists could potentially circumvent some of the issues of power which may come from recruiting within clinical or institutional settings.

Chronically ill and disabled people have been using the Internet to provide different forms of access for themselves for as long as the Internet has existed – the majority of the chronic pain specific Facebook groups I accessed predate COVID-19 by many years. However, it was the practical consequences of the pandemic which forced me to enter some of these spaces and use them to recruit research participants. The Covid-19 pandemic forced me to use approaches from within both online ethnography and disability studies to access participants via online, community-run spaces, producing a very interesting kind of access.

Access to different spaces

In England, the Covid-19 pandemic has been associated with numerous “stay at home” orders to reduce person-to-person transmission of the virus and avoid overwhelming pressure on the NHS. In practice, this has meant that (if it was not already) the home has often become a workplace for those not considered “keyworkers,” and a space where the boundaries between work, childcare (including home-schooling), socializing and relaxing become blurred, with much interaction mediated through screens. For the first part of my fieldwork, my research primarily entailed sitting at a desk in my makeshift office, peering into another person’s home through an image beamed via video conferencing software into my laptop.

Voice calling was used on very few occasions, video calls were usually preferred by both research participants and myself. Before our initial conversation, we discussed, usually over e-mail, how to arrange our first meeting. Often video calls were requested by the participant as they allowed visual connection, reassurance that I was a real person, and a feeling of “being there” seemingly not as attainable over the phone. Sometimes these calls were recorded interviews; sometimes they were just an informal chat, depending on the day and what the participant wanted and felt up to.

During the time I spent video calling participants, I saw many different domestic scenes; conversations held in quiet spaces like garden sheds, family members appearing on screen behind the participant for a couple of seconds to wave hello to me, cups of tea being sipped as we spoke. One participant even gave me a tour of her garden as we chatted, proudly showing me the tomatoes ripening on the bushes she had planted outside her house.

Digital and non-digital interruptions occurred during these video calls. Some people (including myself) have patchy Internet connections which can cause communication to become jerky and confusing; a frustration that many people who have used video conferencing software regularly over recent years will share. However, there have been other disruptions too. Sometimes family members would be sitting next to the participant while they talked to me from their sofa, and would contribute to the conversation without me ever seeing their faces. Sometimes cats would walk across keyboards and interrupt the flow of the conversation or press a button they should not have. However, I feel these disruptions contributed further to the aforementioned sense of “being there” and gave me some insight into the daily lives of those taking part in my research.

Doing fieldwork remotely has caused me to access some very strange ethnographic spaces: I am with the participant virtually, but physically detached. This kind of video-mediated space has been written about, to an extent, within literature focused on digital anthropology (Miller and Sinanan 2014). The importance of the choice of technology to communicate is emphasized in this literature, and was seen through the preference of most participants to use Zoom to talk.

However, it is also important to draw from disability studies to think beyond how technology is used to access space, and to think about the importance of space between researcher and participant (Boellstorff 2020; Hartblay 2019). The spatial detachment between participant and researcher discussed above was sometimes very productive. Although some kinds of physical spaces were excluded, the use of video-conferencing software and social media has allowed me to enter other spaces and

communicate more easily with people who are (in their own words) “housebound.” Many people participating in my research have conditions like fibromyalgia, which can cause variable levels of pain and fatigue from day to day. By video chatting with participants, I was able to speak to them if they were in bed or having a “flare up.” This has become increasingly apparent in my research, with participants expressing relief that they are able to speak to me from a comfortable space, and show me “what a bad day really is.”

Access to these intimate spaces during a “bad day” is perhaps not something I could have obtained using wholly offline methods. This ability to talk to people from their beds echoes the “bed space” activism and research which has occurred throughout, and prior to, the pandemic (Piepzn-Samarasinha 2018). While the kind of spaces I have been able to access during the pandemic were not what I anticipated, I also gained access to these important, and intimate “bed spaces.” By speaking to participants from a place of their choosing, I was able to ensure they felt comfortable speaking to me and communicating their feelings and experiences.

One afternoon in April 2021, I got a text from Jennifer, another participant recruited from a Facebook support group. She lives in rural Northumberland, and has a genetic condition that causes her a large amount of pain day-to-day. We were due to talk over Zoom the next day, but over WhatsApp she told me about a hip injury she had sustained playing crazy golf with her sons, texting across to me “thank god I have some canny pain relief that’s all I can say!” When we spoke the next day, I could see that she had answered the call from bed. She looked pale and sad, managing a watery smile as she explained what had happened to her hip. That morning I was able to speak to Jennifer despite the fact she was, at the time, unable to walk due to pain. By video calling Jennifer, I could see her, and talk to her about what had happened without needing to visit her when she was in extreme pain. Throughout the conversation, she was able to stay comfortable in bed. While it is difficult to see someone in pain and not be able to be physically with them, video conferencing software has allowed me to visit spaces which, using more traditional face to face methods, may have been inappropriate or inaccessible.

The kind of care I was able to communicate using video calling software can be understood through Ahlin (2018)’s discussion of care and ICTs in India. Using Ahlin’s material-semiotic framework, care can be understood as being mediated through the interactions between things and people – the webcam became integral to the framework of care which exists between Jennifer and I. Both the choice of technology used, and how it connected two bodies in different spaces, cumulated in research that was comfortable and caring for both of us. This ethnographic example demonstrates how trust and privacy was negotiated in these spaces; the affordances of video calling meant that Jennifer felt comfortable enough to show me a day when she was feeling very unwell.

Without the use of online methods, I would not have been able to see the variable nature of fibromyalgia and other conditions which cause chronic pain. This variability in symptoms is something which many participants have expressed as a frustration when trying to talk about their health with doctors or other clinicians. This variability is now crucial to how I am conceptualizing my research. Incorporating online approaches into research designs, and using online methods flexibly, to see how this variability unfolds, is something that can (and does) hold great methodological utility to medical anthropologists.

Doing fieldwork in remote spaces has also allowed me to do research which holds care as a core value, ensuring accessibility for my participants, and allowing them to show me what it is like to live with chronic pain, in a way they felt comfortable with. As a matter of priority, I had discussed with participants there was never any obligation or need to speak to me when feeling unwell; when I was shown these “bad days” it was entirely due to the participant’s decision to, for example, click the link and join the Zoom call. While it is true that the kind of traditional ethnographic spaces I have been able to access throughout my fieldwork has been limited, I believe that using video conferencing software and text-based communication methods have allowed me to “be there” with participants in a different way, and create research which is sometimes significantly more accessible and representative of reality for those with chronic conditions.

Access to different times

More broadly, how I communicated with people online over the course of my fieldwork has been dictated by the amount of time they were able to give me, or when they felt well enough to talk to me. For some, this has just been an occasional check-in via instant messenger, for others it was regular video calls and lengthy WhatsApp⁴ or text conversations. By checking in with participants using instant messaging technology, I have been attempting to understand more about their daily lives, even when unable to physically be there. In some ways, of course, instant messaging is ethnographically “thin,” often short on detail and lacking the normal visual and verbal cues that would help me to understand how someone is feeling. However, I have found communicating over instant messenger to be surprisingly productive. In fact, I would go as far as to suggest that these online, often asynchronous chats can work as a different kind of participant observation. Being able to get real-time updates without needing participants to log into cumbersome video-conferencing software at a pre-specified time is generating data that I would be unlikely to get through this software alone, or even necessarily through visiting someone in person as part of “normal,” in-person fieldwork.

Through text, I have learned about difficulties accessing prescriptions or getting a GP appointment in a relatively unobtrusive way, without needing to arrange a video call and requiring the participant to be present with me online at a specific time. This has proved especially useful for participants who wanted to take part but simply do not have the time to dedicate to talking to me over Zoom, for example those who have spent the pandemic working, caring for loved ones or home-schooling children (or, in some cases, a combination of all three).

In late April 2021, I had a video call planned with another participant, Clare. Our plans to finally, legally, meet for an in-person walk had been stopped by the very persistent North East rain. When I checked my fieldwork phone the morning we were due to call, I saw I’d received a message from her in the early hours. “hi. Please don’t panic (sic.)” the text said “I’m in a&e. Pain off the scale. So a bit srogged (sic.) up. Won’t make the vid call. Sorry. Will txt you when I get home or am on a ward.” I immediately texted her back to wish her well, and sent a picture of my cat (who Clare loves) in the hope it would cheer her up slightly if she was still in hospital. The instant nature of WhatsApp allowed Clare to contact me while she was still in the hospital, and to give me a small insight into how quickly and unpredictably her pain had increased. Doing “normal” fieldwork, I would never have been present with her at that time – I was asleep. Later that day, she texted me to let me know she was back home and was exhausted, but was feeling much better. We debriefed over text and she was able to tell me much more about the pains that had led up to her hospital visit. We then traded some pictures of pets and agreed to try and talk over Zoom, or in person, after she had spent some time recuperating.

An aspect of my fieldwork that has been especially striking are these productive conversations which have occurred over WhatsApp and other instant messaging platforms. Talking to people via this medium was not part of my initial research design, but has emerged as the easiest, most efficient, and least obtrusive way to contact people. Talking over WhatsApp allows for different kinds of access to time to emerge – a kind of asynchronous research. The benefits of instant messaging need to be acknowledged by anthropologists as we move back into doing more “normal” fieldwork. Texting someone to get a snapshot of their day, at a time when they are free to think and reflect, is an approach which is certainly not “second best” to traditional ethnographic methods, but can be used to “be there” both intermittently and instantly throughout the research period, without the need to be physically present.

This is important for medical anthropologists. As discussed earlier, part of studying health, illness and disability is understanding how both experiences of, and the material conditions of ill-health can vary over time. The way time is often experienced by disabled people can be theorized using Kafer (2013)’s concept of “crip time.” This is especially useful when considering the kind of barriers people experience when going about their daily lives. As Kafer notes, crip time is the manifestation of

a different orientation to time: “Crip time is flex time not just expanded but exploded” (Kafer 2013:27). When thinking about research we need to incorporate approaches which takes this orientation into account, and allows these differences in temporality to emerge ethnographically.

Overlapping and intersecting access

Doing research during a pandemic, which had to use online methods to be safe, placed a magnifying glass onto how these three aspects of access (to particular people, at different times and different spaces) can be created through the use of digital technologies. I continued to use the techniques I had been required to use during the lockdown periods in the UK well after COVID-19 restrictions were lifted, emphasizing to me their usefulness beyond the bounds of the pandemic, in a world in which digital technologies are an increasingly pervasive part of life. In reality, the flexibility I learned to build into my research design and methodology offered me a nexus of access to specific people, in specific spaces, at specific times.

Using these methods, I was able to “see” certain domestic settings, or glimpse physical and temporal aspects of lives that would perhaps have otherwise been inaccessible to me. As discussed, video calls using smartphones or tablets allowed me to talk to people from their sofas and beds, or another a place of comfort, at a time they were feeling too unwell to meet in person. Using our smartphones to speak using instant messaging services, like WhatsApp, meant I could talk to my participants while they were otherwise engaged, or were in physical spaces (e.g on the bus, or even in the hospital) where it would have been difficult to talk over Zoom. For example, often I would be able to catch up with how participants were doing after they had dropped their children off at school and were getting on with the rest of their day, or even while they were busy looking after their children during the school holidays.

This was also seen when my research began to move between online and offline worlds: I was able to go for a walk with someone, and then text them a few hours later to check in with them and see how they were feeling. Sometimes my participants would have had additional thoughts about what we had discussed at our in-person meeting, and so data collection (and proximity to my participants) would trace from an in-person meeting, into a WhatsApp conversation later in the day or the following day. Through these general examples, it is possible to see that the kinds of access I have described in this section can overlap and interact to further blur the lines between the physical and the virtual, or the online and the offline. To create a research design which aims to take advantage of the possibilities that digital technologies can offer is to create a research design which has the potential to create access across and in-between people, space and time.

Epistemic and ethical consequences

The COVID-19 pandemic has resulted in a global change in the way the Internet is used, in a manner not seen during any previous health crises. Arguably, this change exemplifies the banality of contemporary Internet use as outlined by Hine (2015). This banality is important: the pandemic forced an epistemological change in my research approach. The use of the Internet for sociality by chronically ill people is not something exceptional, but something everyday and essential.

Knowledge of this should have existed regardless of the limitations placed upon my ability to do “offline” fieldwork, through an engagement with the idea of “disability anthropology” as articulated by Hartblay (2020). One epistemic consequence of the pandemic for me, and I believe for many other medical anthropologists, is the need to engage with methodological and theoretical approaches utilized within disability studies with the express aim to create research centered around the idea of justice (Hartblay 2020:27). This kind of approach has been used effectively by those working at the intersection of disability studies and digital anthropology (see: Boellstorff 2020; Hartblay 2019). In future, medical anthropologists, especially those working on disability and chronic illness, need to utilize these approaches to hold flexibility, access and justice as core epistemic tenets.

Further to this, when thinking about how to approach research that crosses the (always fluid and flexible) boundaries between online and offline worlds, we need to draw from the kinds of ethical approaches developed by online researchers, while also considering the ethical challenges specific to health research which lingers at the borders of online and offline spaces. When doing any research remotely, it is important to hold care as a core ethical value and have an awareness of the very real differences between face to face and remote research. Concepts of care developed within disability studies can help researchers to do this “care work” (Piepzna-Samarasinha 2018), again reiterating the importance of engaging with both anthropology and disability studies to create thoughtful and ethical research.

To do this, we can incorporate ethical perspectives used by online researchers. The AoIR (Association of Internet Researchers) guidelines provide a useful starting point in navigating the ethics of online research (Markham and Buchanan 2012). In alignment with broader research ethics guidelines, an emergent and contextual approach which aims to prevent harm at all costs is endorsed. These guidelines also offer specific guidance for doing research using social media data or Internet forums. For example, the AoIR guidelines note that ideas around “public” and “private” become complicated during online research, and emphasize importance of asking consent before, for example, joining a private Facebook group for research purposes. As mentioned earlier, before joining the chronic pain support groups I am a member of, I contacted group admins directly and asked for permission to post my recruitment resources on the page. By doing so I ensured that I was respecting the private nature of these groups, and confirmed that posting recruitment materials was an appropriate thing to do in that online space. By using practical approaches to ethics developed by online researchers, I was able to interact with these very private support groups in a way which was committed to the principles of care and respect.

These ethical challenges are not just limited to the practicalities of carrying out some, or all, of research projects online. As discussed earlier, the question of inequity in Internet availability brings with it questions about representation and accessibility. A full discussion of Internet access and research is beyond the scope of this article, but must be platformed as a key ethical and epistemic issue to be addressed further in the future by anyone interested in researching illness and disability. At the same time though, the use of the Internet to do research with people who are chronically ill and/or disabled has been shown to present wonderful possibilities for research which not only is accessible, but holds care as a core value. This is something which should be considered by medical anthropologists in future.

Conclusion

Over the last 20 years, the Internet has merged with the “offline” lives of many. The COVID-19 pandemic has accelerated this, demonstrating that the distinction one might make between “online” and “offline” is not (and to be honest, never has been) dichotomous. The pandemic has disrupted social lives, requiring mediation through screens or masks, and creating a persistent fear of contagion. These barriers have forced those of us currently conducting fieldwork to reconsider how we can continue to do our research meaningfully, and what affordances and challenges may come with moving ethnographic research online temporarily.

I have provided here a brief overview of the parallel histories of online ethnography and disability studies and the Internet. I have argued that the COVID-19 pandemic has highlighted and reiterated the possibilities which doing research that moves within and between online and offline spaces can bring, but that these possibilities must be grounded in an awareness of what has come before. As a medical anthropologist who studies chronic illnesses, learning about this history and applying it to the very complex situation I found myself in in March 2020 has been crucial to my development of what I hope is an accessible and (to the highest possible extent) inclusive research methodology.

I also discussed the challenges that emerged when research designed to be undertaken in offline, physical spaces, was moved entirely online. Doing pandemic fieldwork has warped the kinds of access to people, space and time I have been able to have over the course of my research so far. The pandemic has limited my access to many of things which could, traditionally speaking, allow me to do ethnographic fieldwork. However, I have been able to draw from the methodologies and approaches used by online ethnographers and from within disability studies, to engage with research participants in different, and often very useful, ways. Doing this has allowed me to create a flexible methodology, which jumps between and across online and offline spaces to give me interesting insight into my participant's lives.

Furthermore, doing research in this way has created novel epistemic and ethical consequences which will become of increasing importance to medical anthropologists in future. As noted throughout this article, Hartblay (2020)'s concept of disability anthropology is good to think with in this regard. Using online methods to do research with chronically ill and disabled people can be an act of care. However, doing research which makes full use of the possibilities of the Internet requires an awareness of (1) the specific ethical challenges doing research online presents and (2) the broader ethical issues which come alongside using the Internet to do health research in a world where Internet access is linked very closely to health inequality.

My experiences doing fieldwork in the middle of a pandemic have required me to be flexible in many different ways; practically, personally, methodologically and epistemically. The implications of this flexibility, I feel, are especially important for those of us who use ethnographic methods to do health-focused research. For medical anthropologists, understanding research as being something which can be carried out using multiple different methodologies and technologies has the potential to encourage the production of multifaceted research designs. By ensuring different forms of access (which extend across physical/virtual, or offline/online boundaries) are built in as in integral, central tenet, medical anthropologists can ensure a focus on exploring further the diversity of experiences that can surround health and illness.

When I started my PhD in October 2019, I picked up a copy of Anna Tsing's "The Mushroom at the End of the World" in an attempt to make myself think about ethnography again. Now, two and a half years and one pandemic later, I consider the opening words from the prologue in a different light: "what do you do when your world starts to fall apart? I go for a walk, and if I'm really lucky, I find mushrooms" (Tsing 2015:1). When I proposed my PhD project, I did not under any circumstances imagine I would be doing it while navigating through a pandemic. The world did fall apart – the COVID-19 pandemic has exposed the raw center of the precarity which Tsing writes about so extensively in *The Mushroom at the End of the World*. Doing ethnographic research during COVID-19 has been (and still is) tricky, erratic and stressful. But, doing research like this has allowed me to think in unpredictable ways about why I want to do this research, and has emphasized the importance of using a variety of ethnographic methods to work with the participants who have offered to share their stories, and their lives, with me. Moving my research online has caused me to think through every decision I've made multiple times, constantly evaluating the reasons for every choice I've made and opening doors which may have remained shut, had I stuck to my original research outline. This flexibility is something which should have been built into my research design from the start.

Despite the limitations which emerge when trying to do research which flits between online and offline spaces, I believe that medical anthropologists should be making concerted efforts to use online methods in their research. I hope that this article provides some insight into my experiences, and provides space for medical anthropologists to think further into the future, about doing research not only in the post-Covid world, but also in a world where online and offline spaces are increasingly merged, and the importance of information technologies is only set to grow.

The approaches discussed in this article hold importance well beyond the bounds of the pandemic. When doing research which is focused around health and disability, online or remote methods can vastly increase the accessibility and flexibility, and perhaps even the kinds of participation in research.

This is especially pertinent as we look forward to the “new normal” which has been central to the collective imaginations of many throughout the pandemic. I hope the accounts of my experiences which form the body of this article might contribute to future conversations about how we can do research which benefits health, in a complex world that is ever-more entwined with Information Technologies. As Pandian (2019:4) argues, anthropology can allow us to “trace the outlines of a possible world within this one.” As the potential for a post-pandemic future appears on the horizon, we need to look to the past and consider the ways online ethnography and disability studies can help medical anthropologists to engage with, understand, and improve, post-pandemic life.

Notes

1. I accessed local chronic pain support groups on Facebook, after asking permission from an admin to post my research materials on the site.
2. On some occasions, participants saw my information sheet (which included a phone number and e-mail address) posted on one of the Facebook pages, and got in contact with me directly expressing interest in taking part, either via phone or e-mail. I had a research fieldwork phone I used specifically for this purpose, to allow me to post my phone number openly on the Internet without risking my personal data. There were also a few cases where participants did not feel confident or able to use Zoom or e-mail, so we spoke over the phone or via WhatsApp from the start.
3. I would often take fieldnotes as we were talking, to avoid the pressure of my participants speaking knowing they were being recorded, and perhaps inadvertently to also to try and mimic what would have been happening if we had met ‘in person.’ I would then write these notes up into full fieldnotes after the call had finished.
4. Often the medium preferred by participants due to their familiarity with it and ability to access it over WiFi.

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Notes on contributor

Lucy Johnson is a doctoral candidate at Durham University. Her research focuses on the use of opioid painkillers in the management of chronic pain.

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