Sharing uncertainty: Comparing patient narratives of help-seeking in the first year of the Covid-19 pandemic across the UK, USA, Brazil, Germany and Spain

Anna Dowrick [a,*], Jane Alice Evered [b], Alicia Navarro Dias de Souza [c], Anne Thier [d], Maria Inês Gandolfo Conceição [e], Christine Holmberg [d,f], Vinita Mahtani-Chugani [g]

[a] *University of Oxford, Oxford, UK*
[b] *University of Wisconsin-Madison, Madison, WI, USA*
[c] *Faculty of Medicine, Federal University of Rio de Janeiro, Brazil*
[d] *Institute of Social Medicine and Epidemiology, Medical School Brandenburg Theodor Fontane (MHB), Brandenburg an der Havel, Germany*
[e] *Institute of Psychology, University of Brasília, Brazil*
[f] *Faculty of Health Sciences Brandenburg, Joint Faculty of the Brandenburg University of Technology Cottbus - Senftenberg, The University of Potsdam and the Brandenburg Medical School Theodor Fontane, Potsdam, Germany*
[g] *Research Unit University Hospital Nuestra Señora de Candelaria and Primary Care Management, Ctra. Gral. Del Rosario, 145, 38010, Santa Cruz de Tenerife, Spain*

ARTICLE INFO

ABSTRACT

The early stages of the Covid-19 pandemic generated profound global uncertainty that disrupted health systems. This paper examines uncertainty about Covid-19 from the perspective of patients who sought clinical help in Spain, the UK, the USA, Brazil and Germany in 2020. We conduct a narrative analysis to explore how patients sought to involve health care teams in addressing the ontological and epistemological uncertainties of Covid illness. Patients wanted clinical support to make sense of Covid as a novel illness and interpret their journey to recovery. Access to this support varied. Help-seeking was enabled when health services perceived patient needs as legitimate, alongside an infrastructure that enabled them access to care despite health system strain. In Brazil and Spain, candidacy for support in the early stages of illness was unquestioned, whereas in Germany, the UK and USA patients had to convince health professionals to support them. Where patients did access clinical support, they valued clinicians sharing the work of developing knowledge that would address epistemological uncertainty about Covid. Patients valued clinicians' *potential* to acquire relevant expertise, rather than what they knew about Covid in a given encounter. Comparing experiences across different national settings demonstrates that patients wanted health systems to engage in the uncertainty of the pandemic through being accessible and present during novel illness experiences, sharing responsibility for learning more, and having a curiosity about the unknown.

1. Introduction

1.1. Pandemic uncertainties

Pandemics generate profound global uncertainty. Efforts have been made to characterise different aspects of pandemic uncertainty and the relative attention they receive in terms of policy and research. Kelly et al. (2020) note, for example, that rapid mobilisation of epidemiological knowledge during the Zika pandemic had the consequence that 'some epistemic deficits were quickly and effectively addressed, while others were allowed to persist and become entrenched'. Their examination of engagement in uncertainty during Brazil's Zika crisis revealed that global health uncertainty (understanding causative links between illness and impacts) received greater attention than public health uncertainty (determining who was most at risk) and clinical uncertainty (knowing how to offer equitable standards of supportive care for those most affected).

A similar imbalance has been noted during the Covid-19 pandemic.

In their cross-country analysis of stakeholder and public experiences of the Covid-19 pandemic, Cristea et al. (2022) identified four key areas of uncertainty: epidemiological; information; social; and economic. They found an incompatibility between policy stakeholders' emphasis on addressing epidemiological uncertainty and the public's interest in demystifying the social and economic impact of the pandemic on everyday life. Decoteau and Garrett (2022), examining the Covid response in Chicago, USA, similarly identify a prioritisation of investment in building disease surveillance infrastructure rather than developing knowledge to support efforts to address the social determinants of Covid susceptibility. Dowrick et al. (2023) found that the main uncertainties that troubled day-to-day life in the first year of the pandemic were confusion about transmission and duration of illness. Foregrounding research that addresses causes of illness, while important, leaves other issues less understood, such as how to optimise health system capacity during crises, the socio-economic impact of the pandemic, or illness trajectories. In this paper we seek to address this imbalance, giving attention to patients' concerns in relation to the uncertainties of Covid illness during the first year of the pandemic and how this connected with their expectations and experiences of help-seeking.

We examine uncertainty about Covid-19 from the perspective of patients who sought clinical help in Spain, the UK, the USA, Brazil and Germany in 2020. These countries are part of an existing research collaboration called DIPEx International. During the pandemic the collaboration directed efforts towards comparing Covid experiences across different national settings. The health systems of the five countries are organised according to a range of publicly funded/insurance-based models, and approached the provision of health care and support during the first year of the pandemic in different ways. Studying patient experiences of these differences provides an opportunity to explore how patients wanted health systems to engage in uncertainty and offers lessons for future pandemics.

1.2. Illness, uncertainty and help-seeking

Illness fundamentally disrupts a person's sense of identity (Bury, 2001) and involves '*agentic efforts to make sense of, and to adapt to, illness in the face of immediate and existential uncertainty*' (Whooley & Barker, 2021, pp. 277–278). During past pandemics patients have turned to authoritative sources of medical information to resolve uncertainties (Cristea et al., 2022). Bury (2001) identified that medical input is one of the resources that people draw on to bring coherence to illness narratives. In this respect the uncertainty of illness is both a subjective experience and a relational concern managed between patients and healthcare professionals (Stivers & Timmermans, 2016). Mackintosh and Armstrong (2020) characterise negotiation of uncertainty in healthcare encounters as shared 'uncertainty work'. They highlight differences between epistemological and ontological uncertainty. The former relates to situations where biomedical knowledge about how to address illness is uncertain. Ontological uncertainty refers to situations where the nature of ill-health itself is questioned, typically where there is debate around diagnostic categories. This is often in relation to contested illnesses, such as personality disorders (Pickersgill, 2011), autism (Hollin, 2017) and post-viral illnesses (Dumes, 2020).

Those who fell ill during the first year of the pandemic were troubled by questions regarding how severe or enduring illness would be and how it could be remedied (Koffman et al., 2020; Yuan & Robert, 2021). Involving healthcare professionals in the work of creating a coherent narrative in relation to the uncertainty of Covid illness experiences was challenging. Patients faced over-burdened health systems, limited biomedical knowledge about Covid and few options for medical intervention (Zinn, 2021). Eligibility to access healthcare is a negotiation between patients and health services, requiring navigation of the ontological uncertainty of ill-health. Becoming a legitimate candidate for support from health services is influenced by individual identity and socio-economic contexts, macro-level structures and how resources are allocated, how systems define patients as appropriate objects of healthcare attention and intervention, and the decisions and actions of those providing care (Dixon-Woods et al., 2006). When health systems are under pressure, experiences of patient candidacy change, with legitimacy of help-seeking called into question relative to perceived severity of illness. Patients were therefore presented with additional work with regards to ontological uncertainty in determining whether they were an eligible candidate for health services support during peaks of the pandemic (Baz et al., 2023; Pujolar et al., 2022). Debates over legitimacy of patient needs risk creating situations of epistemic injustice (Fricker, 2007), where ontological uncertainty is invoked to question, ignore or silence claims to candidacy. Across this paper we examine and compare patient narratives of navigating candidacy for support across different health systems in the UK, USA, Germany, Spain and Brazil.

1.3. Caring through uncertainty

For patients who did access care during the first year of the pandemic, interactions involved significant epistemological uncertainty given limited understanding of the nature and trajectory of Covid (Koffman et al., 2020). How clinicians engage with uncertainty is an important aspect of patient care, and was particularly crucial during the pandemic when patients were experiencing multiple changes in all aspects of life. Gross (2007) offers a useful classification of how unknowns can be approached. *Non-knowledge* refers to forms of uncertainty where the limits of knowing are taken into consideration for future planning and action, whereas *negative knowledge* refers to instances where the unknown is actively ignored or discounted. Non-knowledge reflects what McGoey describes as the '*generative and performative nature of uncertainty*' (McGoey, 2009: 155), in that uncertainty can produce activity to address it.

For example, Stivers and Timmermans' (2016) study of conversations about inconclusive genetic tests for children found that even when geneticists lacked answers, their engagement in addressing parents' underlying existential concerns and commitment to using an absence of knowledge to direct future investigations led parents to feel cared for. Similarly, in their study of lower back pain, Costa et al. (2022) found that open discussions about uncertainty were preferable to false certainty or a neglect of discussion about the unknown. Successful caring in the context of clinical uncertainty involves a continual re-alignment and adjustment of practice in relation to what is known and unknown and the multiple potential versions of 'good care' this creates (Pols, 2015). Mol, Moser and Pols (2010) represent this work as '*persistent tinkering in a world full of complex ambivalence and shifting tensions*'' (ibid: 14).

Conversely, when medical uncertainty is characterised by negative knowledge, with the unknown considered unimportant, this can '*call into question at a deeply felt, existential level the cause and legitimacy of symptoms, quality of life, and future plans*' (Stivers & Timmermans, 2016: 200). Lian et al. (2021), for example, found that where General Practitioners (GPs) approach uncertainty indirectly and in a depersonalised manner this negatively impacts consultations and patient rapport. Drawing on these classifications of the unknown we aim to build an understanding of how patients valued the way uncertainty was approached in the care they received from health care services, offering lessons for future health care emergencies.

1.4. Contribution of the paper

Using illness narratives (Bury, 2001) to identify stories of success and disappointment in attempts to seek help enables interpretation of the aspects of uncertainty work that were important for patients to distribute, and how they judged success in sharing the labour of making sense of a novel illness. We focus our analysis on the role of healthcare services in forming coherent narratives during a time of illness and global crisis. We explore how patients felt they were made to matter through the care they received from healthcare services during a time of

upheaval (de la Bellacasa, 2011). Through contrasting experiences in Spain, the USA, the UK, Brazil and Germany, we aim to provide insight into what influenced differences in patients' experiences of sharing uncertainty with clinicians during the pandemic, connecting this with different models of healthcare delivery in each nation and different approaches to pandemic management. Table 1 summarises some of the key differences between countries, which we examine in more detail across the paper. Further information and additional links to policy documents are available in the Appendix.

2. Methods

2.1. Data collection

This was an interview-based qualitative study with a focus on analysing patient narratives of help-seeking in the first year of the pandemic. Data collection occurred between July 2020 and November 2022. The interviews were collected using a comparable narrative and semi-structured approach. All researchers are members of the DIPEx International collaboration (Ziebland & McPherson, 2006), and received the same training and support in interview methodology. Interviews were conducted at a time that suited the participant in the language of choice of the participant. All authors contributed to interviewing. The majority were conducted online. The spread of time from initial illness to interview ranged from four weeks to a year. All were recorded on audio and/or video according to participant preference. Interviews lasted between 45 min and 2.5 h, with a median length of 97 min .

The first section of the interview invited participants to relate how they first became aware of Covid 19, their own experience of the illness and its aftermath. The second section included a semi-structured topic guide with a variety of prompts about how Covid had affected their health and wider aspects of their lives, communities, finances, work, education and family and interactions with health care services. This interview guide was collectively developed by members of the DIPEx International collaboration in 2020.

2.2. Sampling

The overall interview sample for each country aimed for maximum variation (Coyne, 1997) with diversity in geographical location, occupational social class, ethnicity, severity of illness, gender, household composition and age group. Recruitment was through a variety of routes including clinicians, social media, support groups and snowballing to encourage a wide variety of experiences and perspectives. Relevant research ethics approvals were gained in each country before data collection.

For the purposes of this paper, which addresses experiences of Covid-19-related uncertainty in 2020, we included only interviews where people reported experiences of infection with Covid-19 between March 2020 and December 2020. The total number of interviews included in the analysis for this paper was 153: Brazil (41), Spain (23), Germany (26), the USA (22) and the UK (41). An overview of the socio-demographic characteristics of each sample is provided in Table 2.

2.3. Data analysis

Interviews were transcribed and the transcriptions were checked for accuracy. The initial focus of analysis was to examine interview accounts relating to experiences of help-seeking from health care services during 2020. We did not seek to analyse different national policies for service provision, rather patients' narrated experiences of accessing care in each country. Given that this was a cross-country comparative analysis, we focused on primary differences between countries as opposed to within country differences. In the early stages of coding we sought to address the following questions:

Table 1
Summary of impact of pandemic on country health systems.

	Health system	Services/treatment offered during the 1st year of the pandemic	Pressure points in the system
Brazil	A mixed system, with a public service (Sistema Único de Saúde or SUS) providing free healthcare, and a parallel private system used by upper/middle class citizens. Primary care is the initial point of access for health issues within the public system. There is strong continuity of care within primary care services.	Public primary care offered support at clinics and within the community to people affected by Covid.	There were not enough beds at hospitals and primary care clinics were left without enough resources. Limited PPE supplies contributed to health professional infections.
		Private insurance offered telemedicine and appointments at private hospitals.	The shortage of resources was more dramatic in the public than the private health system.
	The majority of medications can be accessed directly by patients through pharmacies without prescriptions. (Paim et al., 2011; Tikkanem et al., 2020)	The Brazilian President controversially promoted hydroxychloroquine, azithromycin and ivermectin for treatment of early/mild, non-hospitalized COVID cases. Physicians within public and private systems disagreed. The President publicly said that Covid was a 'little flu'. He did not support vaccine development or purchase in 2020 (Furlan & Caramelli, 2021; Bento, 2022)	The testing rate for Covid in Brazil was very low, with very high underreporting. (Knaul et al., 2021)
Spain	Publicly funded and provided, free at the point of access National Health Service, decentralised to each Autonomous Community.	Primary care was the front door for Covid assistance, although severe cases were sent to hospitals. Some new infrastructure was developed in some parts of Spain due to high demand.	In the early stages of the pandemic there was not enough PPE for healthcare professionals and also a shortage of staff.
	Primary care services are the first point of access for most health issues, acting as a gatekeeper for the rest of the health service	There was huge variability within the Autonomous Communities in Spain due to differences in incidence of cases and to local organisation of health care services.	Changing protocols overwhelmed health care professionals and had an impact on patients.
	Each citizen has a GP and nurse assigned according to their address, with limited freedom of choice.	Patients were encouraged to stay at home and had phone calls to follow up.	Patients lost trust in the health system due to rapidly changing public messaging.
	The majority of medications are accessed via prescription only through pharmacists. (Bernal-Delgado et al., 2018;	In most places contact tracing was undertaken and special military support (UME) was involved in some places.

Treatment offered was based on the protocols developed by the | (Ruiz-Hornillos et al., 2021; Spanish Ministry of Science and Information, 2023) |

Table 1 (*continued*)

	Health system	Services/treatment offered during the 1st year of the pandemic	Pressure points in the system
	Spanish Ministry of Health, 2023a)	national government. (Spanish Ministry of Health, 2023b)	
UK	Publicly funded, free at the point of access National Health Service (NHS). Primary care services are the first point of access for most health issues. The public can also use a telephone information service called '111' for advice about where to seek help. The majority of medications are accessed via prescription only through pharmacists. (NHS England, 2023)	Patients were encouraged to 'protect the NHS' and ration use of health service resources. Primary care was accessible throughout, but periods of national lockdown limited all but essential access. Those who were severely ill were taken directly to hospital. Contact tracing was undertaken by a privately commissioned service called 'Track and Trace'. The remit of this service was to ensure that people with Covid were isolating and to establish details of close contacts. (Flynn et al., 2020; Talic et al., 2021)	During peaks in infection in April/May 2020 access to hospital-based support was limited to those who were acutely ill. Primary care services remained open but the public found it difficult to access appointments. Access to PPE was difficult across 2020. Inconsistent public health messaging damaged trust in the government response. (Hoernke et al., 2021; Unruh et al., 2022)
Germany	Health care in Germany is a mixed insurance and public contribution system. It is divided into three sectors: outpatient care, the hospital sector, and outpatient and inpatient rehabilitation facilities. Medication as antibiotics are accessed via prescription only through pharmacies. (Busse et al., 2017)	Primary care was the main source of support for people affected by Covid, usually through consultation by telephone with the GP. Local public health departments were responsible for monitoring isolation periods and approving release from isolation after illness. (Federal Joint Committee on Public Health 2020; Robert Koch Institute 2020; 2021)	During peaks of the pandemic there was a lack of PPE and test facilities. In 2020 some people started to demonstrate against the health protection laws established to stop the spread of the Coronavirus. (Frankewitsch, 2022; Naumann et al., 2020)
USA	The healthcare system is largely privately funded in a fee for service for-profit model. A little over a third of the population is covered by public insurance. Eight percent of the population is uninsured, with a great number more underinsured. In the US, there is a protected right to receive emergency care regardless of	During the first year of the pandemic, many health systems were overrun. Primary care was the designated point of access. The use of hydroxychloroquine was authorised by the FDA on March 30th,	During peak infections, about half of low-income communities had no intensive care beds. Access to PPE was inconsistent.

Table 1 (*continued*)

	Health system	Services/treatment offered during the 1st year of the pandemic	Pressure points in the system
	ability to pay, though no universal right to healthcare.	2020, an emergency use authorization that was rescinded in June 2020, after reports of cardiac issues.	
	Primary care services and emergency rooms are the first point of access for most health issues. The majority of medications are accessed via prescription only through pharmacists. (AMJC, 2020; United State Census Bureau, 2021; Sobeski et al., 2021; Vogel et al., 2019)	Covid treatments were offered at no cost to those without insurance under the Federal Uninsured Program. (Lazer et al., 2020; Maganoli et al., 2020; US Department of Health and Human Services, 2021)	Urban centres struggled with the volume of patients admitted to the hospital and intensive care units. (Sandhu et al., 2022)

- What were uncertainties in Covid care in the early days of the outbreaks and how they were experienced?
- Why were these unknowns about Covid 'uncertain' and challenging in healthcare experiences?
- How did these uncertainties shape patients and practitioners' responses in healthcare?

To facilitate the initial stage of coding each country's interview transcripts were imported into specialist computer software for organising textual data for coding (NVivo, MAXQDA & ATLAS.Ti). After collecting together all data relating to help-seeking, the research team in each country developed initial codes using the One Sheet Of Paper mind-mapping approach (Pope, Ziebland, & Mays, 2000), in which all researchers had received training. This involves identifying the key features of each narrative and grouping them together on a single sheet of paper, drawing commonalities between participant accounts. The researchers analysed their own interview data, in the original language. The researchers all had English as either a first or additional language.

All authors attended a series of group online analysis workshops between January and October 2022, and a face-to-face meeting in Switzerland in May 2022 (Chapple & Ziebland, 2018). Across eight workshops the initial coded data were compared, discussed and refined. After initial engagement with the data we identified uncertainty as a central concept raised by participants and refined the focus of analysis to specifically explore the relation between uncertainty and help-seeking during 2020. We drew specifically on Mackintosh and Armstrong's (2020) notions of ontological and epistemological uncertainty to distinguish different aspects of uncertainty relevant to help-seeking. We identified ontological uncertainty as relating to the work of categorising experiences of Covid, with successful help-seeking relating to patients and providers collectively interpreting novel illness experiences as requiring support. We characterised epistemological uncertainty as the work of learning about and acquiring knowledge about Covid. The questions guiding further analysis were:

- How did ontological uncertainty about Covid-19 impact the patient - health care professional relationship in different countries?
- What help did patients seek from healthcare services to address epistemological uncertainty?

Using these as overarching themes, we developed sub-themes using

Table 2
Summary of socio-demographic characteristics of the sample in each country.

	UK	USA	Spain	Brazil	German
Number of interviews	41	22	23	41	26
Age range	21–75	23–65	23–75	26–70	25–82
Gender: male	13	3	7	13	8
Gender: female	28	19	16	28	18
Ethnicity	Focus on ethnic diversity in sample, with 2/3 of the sample minorities	Mostly white sample with 7 people of colour	Mostly white sample	23 white; 16 brown; 1 black; 1 yellow	Mostly white

the same OSOP method. Each country team wrote a two page summary of their OSOP in English and we shared translated excerpts of data. We used workshops to discuss the cultural and health system context of each participant to support shared interpretation, with careful attention paid to the differences in health systems and policies and the circumstances of the participants. We integrated the data at the point when we had developed clear sub-themes, choosing salient examples for each country's dataset. We did not form a specific boundary between people's description of acute and longer-term experiences of Covid, as during 2020 Long Covid was still being developed as a diagnostic category. We focused analysis on the aspects of uncertainty that were considered important to participants, one of which was interpreting recovery.

Subsequent refinements to the line of argument were elaborated by sharing and modifying drafts, which included searching for any examples of deviant cases that contradicted the main findings. Deviant cases were used to modify the boundaries of analytic categories. Analyses were iteratively tested with each country's dataset. Analysis was informed by theoretical insights from the literature, with the aim of enabling theoretical generalisation across the cases (Payne & Williams, 2005; Polit & Beck, 2010). Selected interview extracts were translated by the bi-lingual researchers in preparation for this article. Later drafts were subject to internal review by members of the editorial team of the special issue to which this paper forms a part.

3. Findings

3.1. Seeking accompaniment in illness and recovery

In this section we examine the aspects of help-seeking related to the ontological uncertainty of Covid-19 (Mackintosh & Armstrong, 2020), particularly around understanding and communicating the severity of Covid illness, and the legitimacy of involving health care professionals in the early stages of illness. Help-seeking was successful when health services had loose boundaries for patient candidacy, alongside an infrastructure that enabled access to care despite health system strain.

3.1.1. Negotiating candidacy for support from health services

Across countries, when participants first became unwell with Covid they were uncertain about what to expect through their illness, what constitutes a 'severe experience', and what help was required to safely navigate toward recovery. Public guidance did not adequately address these issues. This led many to desire connection with health care services to provide a structure for what they could expect through illness (Bury, 2001).

The ability to connect with health professionals was different across countries. Participants in Brazil and Spain often reported being directly contacted by primary care professionals during the acute phase of their illness. After initially reporting they had Covid to their GP, Brazilian participants were contacted every day by someone from their primary care unit. Rebeka (Brazil) said '*I had a phone number for the clinic, and they texted every day to see how I was doing*'. Services in Spain also aimed to have regular contact with patients across the course of their illness experience. Ana (Spain), who suffered Covid in the first days of the pandemic, was grateful for her GP's involvement:

The doctor was great, she called me every day, she asked me how I was, she visited several days to examine me, and explained that the pain in my back was because of pneumonia.

Conversely, in the USA, UK and Germany patients struggled to engage health services in their experience. In the USA, expectations for and access to support across the early stages of Covid were minimal. The permeability of services was particularly challenging in the USA, with participants raising that it was difficult to access any primary care services:

As the lockdown began, the clinic got closed, and they didn't, like in the process, the company stopped working with that [um] hospital. So, we didn't have a clinic service for a while, so I didn't have any primary care doctor. And again, I was so, I felt so fragile and so weakened from the sickness, I was a little worried about going out and even going to a doctor's office. (Kim)

Whereas participants in Brazil and Spain were automatically considered candidates for support, those in the USA, UK and Germany had to actively assert their candidacy through demonstrating they had symptoms indicated in public guidance. Where patients were able to get through to services, they faced a further challenge of positioning themselves as 'ill enough' to be prioritised for support. In 2020 the primary symptom used for triaging access to medical attention was 'difficulty breathing'. This meant that those who were experiencing distress as a result of other symptoms struggled to get attention. June (UK), who fell ill in November 2020, felt that you had to be 'dying' to get 'some empathy' from primary health care services.

If you were lucky and got through you had to tell the receptionist practically you're dying and depending on which receptionist you talked to, you might get some empathy and then they might just squeeze you in somehow to speak to a doctor.

Participants considered themselves to be legitimate candidates for support given their severity of illness, and felt disappointed that they had to prove their eligibility to service providers. A German participant, Helene, described her frustration at not being able to access her GP:

You, you feel alone, you feel abandoned. You actually want help, you actually have the expectation that the doctor will help you in some way. And then the door is slammed in your face. So that situation was really bad.

Disappointment at the absence of help available was exacerbated in Germany and the UK, where participants received regular phone calls from contact tracing systems but not support services, reflecting Cristea et al.'s (2022) observation about public frustration in government emphasis on addressing epidemiological uncertainty rather than the personal impacts of the pandemic. Doreen (UK) felt a disjuncture between the investment the government had made in the contact tracing system and the actual care and support available while she was ill.

I felt abandoned because they don't know how I am dealing with Covid here. Ok, I am not at that stage where I need the hospital care but I could need it anytime. You never know if you are going to need it and you could be in a situation where you can't even pick your phone and call 999. I really felt deserted with the whole system, because since they invested so much money in Track and Trace [the government contact tracing system]

they could also phone that person after five days just to see how they are doing, you know, or if they are still alive.

With daily infections, hospitalisation and deaths reported on national media there was a heightened sense that infection could lead to hospitalisation, and potentially death. Health services were positioned as being able to put a boundary on this uncertainty, and the inability to connect or be taken seriously as a candidate for support led to profound feelings of disappointment, abandonment and desertion.

3.1.2. Navigating the progression of illness

Differences in the way that patients were able to connect with health services impacted on the ontological work of interpreting the progression of illness. In contrast with participants from Spain and Brazil, patients in Germany, the USA and UK were left with a double burden of being required to determine if they were getting worse based on limited understanding of the progression of Covid, and also to make the case for why they needed medical input. They ran the risk of their concerns not being taken seriously, representing a form of epistemic injustice (Fricker, 2007).

In Brazil and Spain, ongoing interaction with professionals helped patients to make sense of the progression of illness. Anderson (Brazil) described conversations with a primary care professional while he was unwell:

And he [health professional] sent a message and I replied: "how am I doing?"; [health professional:] "if you are not well, you can come here so we can evaluate you …". [him:] "I am in a lot of pain today", but at no time did I get worse to the point of having to come to the health unit… they were always talking to me, assisting me all the time. "Do you need anything?", "How are you feeling today?", "Are you better?", so I didn't feel alone at that moment, I felt supported and well attended to.

In this example, co-constructing a narrative through conversation with professionals helped him to feel less 'alone' in a profoundly uncertain time. In Spain, patients described being able to access advice over the phone when they were distressed. Professionals helped them to navigate which services they needed to support them through illness. Nacho and María (Spain) explained their experience of moving between primary care and emergency services for support.

We were calling the health centre several times. In the health centre that the nurse told me "if you feel really bad, call 112, that's what the emergency services are for… you are going to get information from a health worker who is going to explain "well this is happening to you or this isn't happening to you, or I can give you this treatment or I can refer you to this other service."

As discussed above, in the UK, Germany and the USA, patients often had to convince others that they were in need of further help. Professionals here were positioned as arbiters rather than partners. Differences in service configuration could present additional barriers to accessing support. In Germany, a participant described a two-stage assessment before being able to access emergency support, having to be assessed by a primary care clinician first to determine her eligibility.

Then I called 112. That's the ambulance service here. Emergency doctor. Emergency service. And there was a very friendly lady on the phone who said to me, "We won't pick you up, we have to discuss this with your doctor first. Then she took the data from my doctor. Once again I was asleep. At some point there was a phone call from my doctor. […] I had to come to the practice so that my doctor could call the ambulance from the practice and the emergency doctor could be called… (Monika)

Some US participants described a process of having to present to emergency services multiple times as they became increasingly ill in order to access support.

The first time I went to the emergency room, the doctor wanted to explain to me– he was like, "no, you're not an emergency where we say we'll keep

you, but here's the deal. We have people who come back two and three times, and by the third time, we usually decide to keep them by that time. So, you're definitely in the early stages of your Covid, so if it gets worse, then we probably might take you. But at this moment, you're still in the early stages, and [uh] we're not taking you."

Responding to explicit and implicit government messaging about the strain on the healthcare system, some participants actively self-triaged to limit their use of services despite needing help. A US participant avoided seeking urgent care because 'I *wasn't dying and gasping for breath*'. Ambiguity about what constituted a legitimate claim for support meant many participants were left to face Covid alone.

3.1.3. Follow-up after illness

In all countries in this study, navigating access to support, or 'follow-up', after the acute phase of illness was challenging. As well as wanting support in understanding if they were getting worse, patients also valued sharing the labour of creating a narrative of recovery. Government emphasis on crisis management meant that there was minimal investment in addressing people's longer-term experiences. In the early months of the pandemic uncertainty about the duration of symptoms could be a source of significant distress (Dowrick et al., 2023), particularly when symptoms persisted past periods of formal quarantine or official guidance, and before understanding of Long Covid came to light (Maclean et al., 2023). Across countries, participants wanted professionals to be interested in their ongoing experience of Covid. Irene (UK) for example, strongly felt that professionals should have wanted to investigate more about her experience.

I was realising that I had this breathlessness, I also had this pain and everything was like over the phone though. They'd phone, and I just thought like 'wouldn't you just want to just listen to my chest? Take my blood?' No, no, no, no. Absolutely awful. I just think that no nobody took a mental account of, you know, maybe we need to just check up on her in a few weeks' time.

Irene describes an abrupt ending in her interaction with health care services, despite feeling ongoing vulnerability in relation to pervasive symptoms and how Covid might impact her ongoing illness. A participant from Germany (Helene), similarly spoke about the lack of advice available from medical professionals about their ongoing symptoms. She said: '*You were left completely alone.What I found so bad that no one can really tell you what will happen next year. Will we be all right in a year's time?'* Uncertainty about how to interpret the process of recovery, teamed with the unpredictability of the progression of the pandemic, brought a feeling of hopelessness.

Contrasting these positive and disappointing experiences, we interpret that help-seeking activities aimed to produce a feeling of being accompanied in constructing a narrative about a novel illness that had unpredictable outcomes. In the next section, we explore patient experiences of sharing the epistemological labour of learning about Covid with professionals.

3.2. Sharing epistemological uncertainty

In this section we focus on how participants ascribed roles for addressing the epistemological uncertainties of being ill with Covid, given the limited biomedical knowledge available about Covid in the early stages of the pandemic. In instances where participants described encounters with health care professionals, patients valued clinicians' positioning of the unknown of Covid experiences as non-knowledge (where the unknown motivates further enquiry) as opposed to negative knowledge (where the unknown is dismissed as unimportant) (Gross, 2007). They valued clinicians' *potential* to acquire relevant expertise, rather than what they might know about Covid in a given encounter.

3.2.1. Approaching the unknown with curiosity

Participants across countries acknowledged that patients and professionals were both facing something unknown. June (UK) appreciated that '*the medical profession do not know a lot about it*', and Laura (US) recognised that, "*the uncertainty of this, that's got to be a hard one, a hard one on both ends of the equation.*" Elisa (Spain) reflected that her doctor was '*just as lost as I was*'.

> *I think we all have that feeling that doctors have to know everything, they have to do everything well and be up to date, but nothing could be further from the truth, she was just as lost as I was, and it is normal because the protocols changed every month or even more, not much was known and she had more patients.*

Despite the lack of knowledge or intervention available to the medical professions, participants rarely blamed health care professionals for not knowing how to support them. Broadly, clinicians were judged on their interest in learning from emerging knowledge and ongoing interactions with patients, what Gross (2007) would classify as a concern with non-knowledge. Not knowing about Covid at first was defensible, but failing to use uncertainty as a motivation to learn more was indefensible. Ann (US) describes her frustration when clinicians didn't demonstrate a developing knowledge about her persistent symptoms:

> *I got so frustrated with my lack of care that I was getting, and their lack of knowledge. Like I just feel like they don't get it. I don't understand. Like I just don't understand what they're not, like are they learning as this, are they picking up, are they keeping themselves informed? Obviously, things change every day, but are they really taking the time to understand this?*

This participant equates a lack of care with a lack of effort on the part of the clinician to '*take the time to understand*', that is, to treat ignorance as something that could be productive (McGoey, 2009). Patients, who were undertaking daily work to make sense of symptoms, wanted healthcare professionals to similarly seek opportunities to learn within their own remit of expertise. This emphasis on professional commitment to learning arose in multiple accounts. Another participant from the USA expected her clinician to be acquiring new knowledge:

> *They should be able to learn, you know, on this learning curve. I mean, we're all learning, yeah, this is all new. But if they're the ones that, you know, have to address it, I guess you kind of feel helpless.*

This participant connects their help-seeking with a desire for a clinician to take their share of responsibility to address the epistemological uncertainty of Covid, drawing on access to biomedical knowledge that was unavailable to the public. The absence of this left the participant feeling help-*less*. Conversely, there were narratives of successful encounters, such as when clinicians discussed rapidly evolving scientific knowledge with participants. Carol (USA) expressed how learning about possible aetiologies of her persistent symptoms lessened the fear she experienced:

> *We even had conversation like because there's lots of [um] there's lots of theories out there about why this is happening, you know, scientists and doctors and things that are addressing it. And, you know, so I had a conversation with him about what he thought… So, you know, it was good to talk to him about it and him to understand. You know, that was, [um] helped with the fear.*

The burden of living through the epistemological uncertainty of Covid was made lighter in by naming it, and attempting to take action despite it. Several people described how they appreciated when clinicians would address uncertainty outright, though only if this was accompanied by the aforementioned openness to learning more. Marianna (USA) liked that her clinician '*doesn't know everything or claim to know everything.*' Similarly, in Brazil, Poliana recognised that '*it was difficult for him [her doctor] to know what to do*'. She expressed confidence in the relationship with him because he shares his uncertainty and acts

cautiously in the face of the absence of consistent information. She felt they were in '*the same boat with uncertainty*':

> *So, even the doctor, I remember that until today, the doctor said "look, what do you think, let's start with this protocol, but look, after four days, Poliana, four days of treatment, if you don't notice that the medication is working, you come back here, you come back and then we will do this monitoring", then I "okay". So, it's even this security in uncertainty, to assume this uncertainty, that we are in the same boat with uncertainty, so to speak.*

Participants also valued being treated as a legitimate source of knowledge, in contrast to examples of epistemic injustice (Fricker, 2007) in the previous section where their knowledge claims were dismissed. A German participant, Tina, described a positive encounter with a GP who said '*I really don't know. You know more than I do, you are experiencing the disease. Tell me about it*'. Mariana (US) similarly reflected: '*He really does approach it as that partnership and also, like, I am someone that he is learning from, you know what I mean?*' Robert, from the UK, had a doctor who he felt was 'patient' and 'eager to find things out' when he fell ill with Covid.

> *When she called me back the way that she interacted with me, the way that she was so patient and eager to find out things first to work through. I think that maybe it could be that because she has so many Covid patients, she actually tries to gain data and information from everyone to see the similarities, to find out if they're, they're different types of prescriptions or medicines that could be given, you know, to help. So, it's sort of trial and error right now.*

These examples demonstrate that, across countries, participants valued care that drew on the emerging expertise of both patients and professionals and involved an orientation towards the unknown as something to be actively engaged with (Gross, 2007). What was central to these positive interactions was humility about what was unknown, and the sometimes greater expertise of the patient, alongside curiosity and openness to learn more. A trial and error approach to care, a tinkering (Mol, Moser & Pols, 2010) in light of emerging information, was desired by patients. Fear of the unknown was countered by collectively treating it as something to be explored rather than ignored (Gross, 2007).

3.2.2. Disputed unknowns

As well as contending with uncertain knowledge about how to address Covid, participants also had to address contested knowledge. Access to emerging treatments was different between countries, with Brazil representing a deviant case in this respect. The Brazilian president at the time - Jair Bolsonaro - controversially recommended hydroxychloroquine, azithromycin and ivermectin for treatment of early/mild, non-hospitalized COVID cases.

Some Brazilian patients sought these treatments, but encountered few healthcare professionals who would prescribe them. In some instances this led to rupturing of relationships, with patients seeking other professionals who would prescribe them or directly self-medicating. Other patients felt mistrustful of professionals who did suggest these medications. Humberto (Brazil) was recommended to take chloroquine by his doctor and felt regret for not having challenged this:

> *Chloroquine in Brazil has become a political medicine, right, it has become something that shouldn't be part of real medicine, and for me too, right, so I already had a certain aversion to it, and then I just left, right, I didn't say anything like that, and one thing I regret is not having questioned this doctor, you know, "okay, but so what? Will you prescribe it to me, how? Based on what are you talking about? Because from what I'm seeing, from the things I'm reading, the scientific evidence is saying that they have no effect, that it's even dangerous, right, so how is it, like that?"*

The promotion of questionable treatments by those outside of spheres of clinical or patient knowledge exacerbated epistemological

uncertainty and increased the possibility of conflict between patients and healthcare services.

4. Discussion

We have examined the care that people hoped for and sought in relation to the ontological and epistemological uncertainty (Mackintosh & Armstrong, 2020) of Covid-19 in the first year of the pandemic. We have characterised the similarities and differences in how participants in Spain, Brazil, the USA, the UK and Germany engaged with healthcare providers. While a desire for interaction with health services in order to provide structure to a frightening experience was pervasive among patients interviewed, the ability to connect, and moreover to connect in a way that reduced the burden of uncertainty, differed between country contexts. Our novel contribution to understanding help-seeking in the first year of the pandemic in articulating that patients were not necessarily seeking answers, but were seeking support in constructing an illness narrative that made the unknown productive.

Through comparing narratives of successful and unsuccessful help-seeking, we noted significant differences in participants' ability to present as legitimate candidates for support from healthcare systems. In the USA, UK and Germany service configuration focused on supporting only those who were characterised as severely ill with regard to the respiratory impact of Covid, rendering other claims to candidacy for support illegitimate. System-level contact with patients aimed to address epidemiological uncertainty through contact tracing, which conflicted with patient desire for support in navigating the everyday uncertainties of illness experiences. This reinforces findings from Kelly et al. (2020), Cristea et al. (2022) and Decoteau and Garrett (2022), who similarly identified disjunctures between state and public interest in addressing uncertainty. In Spain and Brazil, long-standing relationships between patients and primary care services reduced gate-keeping, meaning that clinicians could proactively designate patients as legitimate candidates for healthcare support.

Challenges in navigating ontological uncertainty as a patient were shaped at the level of the health system, dictated by overall expectations of support from states. This highlights that the work of categorising uncertainty can serve to exclude people from support (Mackintosh & Armstrong, 2020), particularly where diagnostic categories connect with mobilisation of resources and access to care (Jutel & Nettleton, 2011). In systems where there is open but rationed access to direct support, such as the UK and Germany, ontological uncertainty exacerbates existing debates about the legitimacy of help-seeking, and how much uncertainty patients are expected to tolerate alone. This discourse was absent in Spain and Brazil, where support was available and accessible regardless of perceived illness severity. The USA was an outlier, with minimal expectations of direct support, reflecting the overall absence of expectation of state intervention in health and the individual responsibility for paying for care. In all systems there was an expectation for follow-up to attend to concerns about recovery – a key area of ontological uncertainty – but examples of this need being clearly met was only directly articulated among Brazilian participants. This is a notable finding, given the other countries are comparatively highly-resourced health systems.

Investigating ontological and epistemological uncertainty provides understanding of what care in a crisis looks like. The learning from these participants was that patients value support from health services in providing a narrative structure to illness experiences during times of crisis (Bury, 2001). The key areas of uncertainty for participants were how long Covid symptoms would last and their consequences. While the majority of accounts describe situations where both patients and providers lack expertise, and opportunities for intervention prove limited, experiences of 'good' care were still possible. Despite there being limited help available, feelings of helplessness were minimised when it was possible to access healthcare providers who engaged with the unknowns of Covid as non-knowledge (Gross, 2007) or a form of *productive*

ignorance' (Whooley & Barker, 2021), where uncertainty in these instances was met with curiosity on the part of the clinician and spurred further inquiry.

In the context of interpreting ongoing symptoms, patients appreciated a continued commitment to working together to address epistemological uncertainty. Patients valued clinicians' *potential* to acquire relevant expertise, and their interest in learning from patient experiences and honouring lay expertise, as part of an ongoing interaction. This reflects the interpretation of care as processual, involving *'persistent tinkering in a world full of complex ambivalence and shifting tensions*" (Mol, Moser & Pols 2010: 14). What was important in the face of uncertainty was not immediate knowledge, but a shared direction of travel, mirroring experiences of chronic conditions described by Stivers and Timmermans (2016) and Costa et al. (2022). It was through ongoing engagement in the unknown aspects of their experience that patients were made to feel that they matter (Puig de la Bellacasa, 2011), which was considered particularly important in a time of global crisis. Positive clinical encounters in the context of the first year of Covid can perhaps be better characterised by effectively shared uncertainty rather than improved outcomes.

Our analysis suggests that practical options for treatment mattered less than the sense that clinicians and patients were exploring together ways of making things better. This has implications for pandemic management. Clinical support in addressing the unknown of novel illness experiences would be facilitated by effective pandemic learning health systems (Cassidy et al., 2022) that enable clinical teams to rapidly access information that could demonstrate their orientation towards 'non-knowledge' (Gross, 2007). Government prioritisation of addressing epidemiological uncertainty led to continued unknowns about navigating the day-to-day of Covid illness, with negative impacts on patient-provider relationships in some instances. Equipping clinicians with the means to acquire knowledge that addresses the uncertainties that matter to patients will facilitate improved care in future pandemics. We build on the work of Dingwall et al. (2013) into the sociology of pandemic management, in that we highlight the important role of emerging biomedical knowledge in shaping narrative experiences of emergent pandemics.

While the strength of the contributions of this paper lie in the comparison of patient experiences across nations, this approach also has limitations. We have made theoretical generalisations about differences based on the sample of patients we spoke to. While we were consistent in the use of a common methodological approach, data collection was undertaken at different time points across 2020-22 in each country, so stories about the first year of the pandemic may have been told differently depending on the distance from the illness experience.

5. Conclusion

In this study we compared experiences of help-seeking in relation to the uncertainty of Covid-19 illness during the first year of the pandemic across Spain, the UK, the USA, Germany and Brazil. While a desire for support from healthcare services was pervasive among patients interviewed, access to care differed within and between country contexts. Examining help-seeking through the lens of ontological and epistemological uncertainty, we have improved understanding of the role that patients want healthcare providers to take during health crises. Across countries patients sought to be 'accompanied' through novel illness, with medical input sought to construct a coherent narrative of Covid illness. The interactions with professionals that achieved this were characterised by curiosity about patient experiences, honesty about limits of expertise, and active engagement in sharing the burden of uncertainty about illness progression. This form of care was possible in each setting, despite differences in health system structure. Further research could explore how health systems can support professionals to consistently fulfil this role during health crises and how patients can have clear routes of access to support despite the uncertainty of

categorising novel illness experiences.

Funding

CRediT authorship contribution statement

Anna Dowrick: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Roles, Writing – original draft. **Jane Alice Evered:** Conceptualization, Data curation, Investigation, Methodology, Writing – review & editing. **Alicia Navarro Dias de Souza:** Data curation, Investigation, Formal analysis, Methodology, Writing – review & editing. **Anne Thier:** Data curation, Investigation, Formal analysis, Methodology, Writing – review & editing. **Maria Inês Gandolfo Conceição:** Data curation, Investigation, Methodology, Writing – review & editing. **Christine Holmberg:** Data curation, Investigation, Methodology, Writing – review & editing. **Vinita Mahtani-Chugani:** Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Writing – review & editing.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgements

References

American Journal of Medical Care. (2020). A timeline of covid-19 developments in 2020. https://www.ajmc.com/view/a-timeline-of-covid19-developments-in-2020.

Baz, S. A., Fang, C., Carpentieri, J. D., & Sheard, L. (2023). 'I don't know what to do or where to go'. Experiences of accessing healthcare support from the perspectives of people living with long covid and healthcare professionals: A qualitative study in bradford, UK. *Health Expectations, 26*(1), 542–554. https://doi.org/10.1111/hex.13687

de la Bellacasa, M. P. (2011). Matters of care in technoscience: Assembling neglected things. *Social Studies of Science, 41*(1), 85–106. https://doi.org/10.1177/0306312710380301

Bento, K. (2022). "The hysteria of a little flu": Effects of COVID-19 on HEIs in Brazil. *Higher Education.* https://doi.org/10.1007/s10734-022-00887-9

Bernal-Delgado, E., García-Armesto, S., Oliva, J., Sánchez Martínez, F. I., Repullo, J. R., Peña-Longobardo, L. M., Ridao-López, M., & Hernández-Quevedo, C. (2018). España: Informe del sistema sanitario. *Sistemas sanitarios en transición, 20*(2), 1–179.

Bury, M. (2001). Illness narratives: A fact or fiction? *Sociology of Health & Illness, 23L,* 263–285.

Busse, R., Blümel, M., & Spranger, A. (2017). Das deutsche gesundheitssystem: Akteure, daten, analysen. MWV. https://www.bundesgesundheitsministerium.de/zuzahlung-und-erstattung-arzneimittel.html.

Cassidy, C., Sim, M., Somerville, M., et al. (2022). Using a learning health system framework to examine COVID-19 pandemic planning and response at a Canadian health Centre. *PLoS One, 17*(9), Article e0273149.

Chapple, A., & Ziebland, S. (2018). Methodological and practical issues in cross-national qualitative research: Lessons from the literature and a comparative study of the experiences of people receiving a diagnosis of cancer. *Qualitative Health Research, 28*(5), 789–799. https://doi.org/10.1177/1049732317736284

Costa, N., Mescouto, K., Dillon, M., Olson, R., Butler, P., Forbes, R., & Setchell, J. (2022). The ubiquity of uncertainty in low back pain care. *Social Science & Medicine, 313*, Article 115422. https://doi.org/10.1016/j.socscimed.2022.115422. Epub 2022 Oct 3. PMID: 36215924.

Coyne, I. T. (1997). Sampling in qualitative research. Purposeful and theoretical sampling; merging or clear boundaries? *Journal of Advanced Nursing, 26*(3), 623–630. https://doi.org/10.1046/J.1365-2648.1997.T01-25-00999.X

Cristea, F., Weishaar, H., Geurts, B., et al. (2022). A comparative analysis of experienced uncertainties in relation to risk communication during COVID19: a four-country study. *Global Health, 18*, 66. https://doi.org/10.1186/s12992-022-00857-x

Decoteau, C. L., & Garrett, C. L. (2022). Disease surveillance infrastructure and the economisation of public health. *Sociology of Health & Illness, 44*(8), 1251–1269. https://doi.org/10.1111/1467-9566.13514

Dingwall, R., Hoffman, L. M., & Staniland, K. (2013). Introduction: Why a *sociology* of pandemics? *Sociology of Health & Illness, 35*, 167–173. https://doi.org/10.1111/1467-9566.12019

Dixon-Woods, M., Cavers, D., Agarwal, S., et al. (2006). Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. *BMC Medical Research Methodology, 6*, 35. https://doi.org/10.1186/1471-2288-6-35

Dowrick, A., Grob, R., Sawada, A., Thier, A., Holmberg, C., & Sato, R. S. (2023). Navigating responsible bio-political citizenship: Cross-country comparison of stigma in Covid-19 illness narratives in Germany, Japan, the UK and the USA. *SSM Qual Res Health., 10*, Article 100291. https://doi.org/10.1016/j.ssmqr.2023.100291

References

Dumes, A. (2020). *Divided bodies: Lyme disease, contested illness, and evidence-based medicine.* Durham: Duke University Press.

Federal Joint Committee of German Public Health. (2020). Regulations on sick leave. https://www.g-ba.de/presse/pressemitteilungen-meldungen/866/.

Flynn, D., Moloney, E., Bhattarai, N., Scott, J., Breckons, M., Avery, L., & Moy, N. (2020). COVID-19 pandemic in the United Kingdom. *Health Policy Technol, 9*(4), 673–691. https://doi.org/10.1016/j.hlpt.2020.08.003. Epub 2020 Aug 27. PMID: 32874853; PMCID: PMC7451057.

Frankewitsch, A. (2022). Proteste gegen Corona-Schutzmaßnahmen. In H. J. Lange (Ed.), *Politik zwischen Macht und Ohnmacht. Studien zur Inneren Sicherheit.* Wiesbaden: Springer VS. https://doi.org/10.1007/978-3-658-35393-3_9.

Fricker, M. (2007). Epistemic injustice: Power and the ethics of knowing. In *Epistemic injustice: Power and the ethics of knowing.* Oxford University Press. https://doi.org/10.1093/acprof:oso/9780198237907.001.0001.

Furlan, L., & Caramelli, B. (2021). The regrettable story of the "covid kit" and the "early treatment of covid-19" in Brazil. *The Lancet Regional Health - Americas, 4*, Article 100089. https://doi.org/10.1016/j.lana.2021.100089

Gross, M. (2007). The unknown in process: Dynamic connections of ignorance, non-knowledge and related concepts. *Current Sociology, 55*(5), 742–759. https://doi.org/10.1177/0011392107079928

Hoernke, K., Djellouli, N., Andrews, L., et al. (2021). Frontline healthcare workers' experiences with personal protective equipment during the COVID-19 pandemic in the UK: A rapid qualitative appraisal BMJ. *Open, 11*, Article e046199. https://doi.org/10.1136/bmjopen-2020-046199

Hollin, G. (2017). Autistic heterogeneity: Linking uncertainties and indeterminacies. *Science As Culture, 26*(2), 209–231. https://doi.org/10.1080/09505431.2016.1238886

Jutel, A., & Nettleton, S. (2011). Towards a sociology of diagnosis: Reflections and opportunities. *Social Science & Medicine, 73*(6), 793–800.

Kelly, A., Lezaun, J., & Löwy, I. Gustavo Corrêa Matta, Carolina de Oliveira Nogueira, Elaine Teixeira Rabello. (2020). Uncertainty in times of medical emergency: Knowledge gaps and structural ignorance during the Brazilian Zika crisis. *Social Science & Medicine, 246*, 2020. https://doi.org/10.1016/j.socscimed.2020.112787

Knaul, F. M., Touchton, M., Arreola-Ornellas, H., et al. (2021). Punt politics as failure of health system stewardship: Evidence from the COVID-19 pandemic response in Brazil and Mexico. *The Lancet Regional Health - Americas, 4*, Article 100086. https://doi.org/10.1016/j.lana.2021.100086

Koffman, J., Gross, J., Etkind, S. N., & Selman, L. (2020). Uncertainty and COVID-19: How are we to respond? *Journal of the Royal Society of Medicine, 113*(6), 211–216. https://doi.org/10.1177/0141076820930665. PMID: 32521198; PMCID: PMC7439590.

Lazer, D., Santillana, M., Perlis, R., Ognyanova, K., Baum, M., Druckman, J., Volpe, J., Chwe, H., & Simonson, M. (2020). The state of the nation: A 50-state covid-19 survey. https://www.covidstates.org/reports/covid-19-testing.

Lian, O. S., Nettleton, S., Å, W., & Dowrick, C. (2021). Negotiating uncertainty in clinical encounters: A narrative exploration of naturally occurring primary care consultations. *Social Science & Medicine, 291*, Article 114467. https://doi.org/10.1016/j.socscimed.2021.114467. Epub 2021 Oct 9. PMID: 34653685.

Mackintosh, N., & Armstrong, N. (2020). Understanding and managing uncertainty in health care: Revisiting and advancing sociological contributions. *Sociology of Health & Illness, 42*(S1), 1–20. https://doi.org/10.1111/1467-9566.13160

References

Koch Institute, R. (2020). Epidemiological bulletin. https://www.rki.de/DE/Content/Infekt/EpidBull/Archiv/2020/Ausgaben/46_20.pdf?_blob=publicationFile.

Koch Institute, R. (2021). Health department crisis response. https://www.rki.de/DE/Content/Service/Presse/Pressemitteilungen/2021/03_2021.html.

Maclean, A., Hunt, K., Brown, A., Evered, J. A., Dowrick, A., Fokkens, A., Grob, R., Law, S., Locock, L., Marcinow, M., Smith, L., Urbanowicz, A., Verheij, N., & Wild, C. (2023). Negotiation of collective and individual candidacy for long Covid healthcare in the early phases of the Covid-19 pandemic: Validated, diverted and rejected candidacy. *SSM. Qualitative Research Health, 3*, Article 100207. https://doi.org/10.1016/j.ssmqr.2022.100207

Magagnoli, J., Narendran, S., Pereira, F., Cummings, T. H., Hardin, J. W., Sutton, S. S., & Ambati, J. (2020). Outcomes of hydroxychloroquine usage in United States veterans hospitalized with COVID-19. *Médica Sur, 1*(1), 114–127.e3. https://doi.org/

10.1016/j.medj.2020.06.001. Epub 2020 Jun 5. PMID: 32838355; PMCID: PMC7274588.

McGoey, L. (2009). Pharmaceutical controversies and the performative value of uncertainty. *Science As Culture, 18*(2), 151–164. https://doi.org/10.1080/09505430902885474

Mol, A., Moser, I., & Pols, J. (Eds.). (2010). *Care in Practice: On Tinkering in Clinics, Homes and Farms* (1st ed.). New York: Columbia University Press.

Naumann, E., Möhring, K., Reifenscheid, M., Wenz, A., Rettig, T., Lehrer, R., Krieger, U., Juhl, S., Friedel, S., Fikel, M., Cornesse, C., & Blom, A. G. (2020). COVID-19 policies in Germany and their social, political, and psychological consequences. *European Policy Analyst, 6*(2), 191–202. https://doi.org/10.1002/epa2.1091. Epub 2020 Sep 28. PMID: 34616900; PMCID: PMC7537296.

NHS England. (2023). 'An introduction to the NHS'. https://www.england.nhs.uk/get-involved/nhs/.

Paim, J., Travassos, C., Almeida, C., Bahia, L., & Macinko, J. (2011). The Brazilian health system: History, advances, and challenges. *Lancet (London, England), 377*(9779), 1778–1797.

Payne, G., & Williams, M. (2005). Generalization in qualitative research. *Sociology, 39* (2), 295–314. https://doi.org/10.1177/0038038505050540

Pickersgill, M. (2011). Ordering disorder: Knowledge production and uncertainty in neuroscience research. *Science As Culture, 20*(1), 71–87. https://doi.org/10.1080/09505431.2010.508086

Polit, D. F., & Beck, C. T. (2010). Generalization in quantitative and qualitative research: Myths and strategies. *International Journal of Nursing Studies, 47*(11), 1451–1458. https://doi.org/10.1016/j.ijnurstu.2010.06.004

Pols, J. (2015). Towards an empirical ethics in care: Relations with technologies in health care. *Medicine, Healthcare & Philosophy, 18*(1), 81–90. https://doi.org/10.1007/S11019-014-9582-9

Pope, C., Ziebland, S., & Mays, N. (2000). Qualitative research in health care. Analysing qualitative data. *BMJ, 320*(7227), 114–116. https://doi.org/10.1136/bmj.320.7227.114. PMID: 10625273; PMCID: PMC1117368.

Pujolar, G., Oliver-Anglès, A., Vargas, I., & Vázquez, M. L. (2022). Changes in access to health services during the COVID-19 pandemic: A scoping review. *International Journal of Environmental Research and Public Health, 19*(3), 1749. https://doi.org/10.3390/ijerph19031749

Ruiz-Hornillos, J., Hernández Suárez, P., Marín Martínez, J. M., de Miguel Beriain Í, Nieves Vázquez, M. A., Albert, M., Herrera Abián, M., Pacheco-Martínez, P. A., Trasmontes, V., & Guillén-Navarro, E. (2021). Bioethical concerns during the COVID-19 pandemic: What did healthcare ethics committees and institutions state in Spain? *Frontiers in Public Health, 9*, Article 737755. https://doi.org/10.3389/fpubh.2021.737755

Sandhu, P., Shah, A. B., Ahmad, F. B., et al. (2022). Emergency department and intensive care unit overcrowding and ventilator shortages in US hospitals during the COVID-19 pandemic, 2020-2021. *Public Health Reports, 137*(4), 796–802. https://doi.org/10.1177/00333549221091781

Sobeski, L. M., Schumacher, C. A., Alvarez, N. A., et al. (2021). Medication access: Policy and practice opportunities for pharmacists. *J Am Coll Clin Pharm, 4*, 113–125. https://doi.org/10.1002/jac5.1373

Spanish Ministry of Health. (2023a). Overview of national health system. https://www.sanidad.gob.es/organizacion/ccaa/home.htm.

Spanish Ministry of Health. (2023b). Covid-19 technical guidance for professionals. https://www.sanidad.gob.es/en/profesionales/saludPublica/ccayes/alertasActual/nCov/documentos.htm.

Spanish Ministry of Science and Information. (2023). Covid-19 updates. https://www.isciii.es/QueHacemos/Servicios/VigilanciaSaludPublicaRENAVE/EnfermedadesTransmisibles/Paginas/-COVID-19.-Informes-previos.aspx.

Stivers, T., & Timmermans, S. (2016). Negotiating the diagnostic uncertainty of genomic test results. *Social Psychology Quarterly, 79*(3), 199–221. https://doi.org/10.1177/0190272516658770

Talic, S., Shah, S., Wild, H., Gasevic, D., Maharaj, A., Ademi, Z., et al. (2021). Effectiveness of public health measures in reducing the incidence of covid-19, SARS-CoV-2 transmission, and covid-19 mortality: Systematic review and meta-analysis. *BMJ, 375*, Article e068302. https://doi.org/10.1136/bmj-2021-068302

Tikkanem, R., Osborn, R., Mossialos, E., Djordjevic, A., & Wharton, G. A. (2020). Brazil. The commonwealth fund. https://www.commonwealthfund.org/international-health-policy-center/countries/brazil.

United State Census Bureau. (2021). Health insurance coverage in the United States: 2020. https://www.census.gov/library/publications/2021/demo/p60-274.html.

Unruh, L., Allin, S., Marchildon, G., Burke, S., Barry, S., Siersbaek, R., Thomas, S., Rajan, S., Koval, A., Alexander, M., Merkur, S., Webb, E., & Williams, G. A. (2022). A comparison of 2020 health policy responses to the COVID-19 pandemic in Canada, Ireland, the United Kingdom and the United States of America. *Health Policy, 126*(5), 427–437.

US Department of Health and Human services. (2021). community based-testing sites for covid-19. https://www.hhs.gov/coronavirus/community-based-testing-sites/index.html.

Vogel, J. A., Rising, K. L., Jones, J., et al. (2019). Reasons patients choose the emergency department over primary care: A qualitative metasynthesis. *Journal of General Internal Medicine, 34*, 2610–2619. https://doi.org/10.1007/s11606-019-05128-x

Whooley, O., & Barker, K. K. (2021). Uncertain and under quarantine: Toward a sociology of medical ignorance. *Journal of Health and Social Behavior, 62*(3), 271–285. https://doi.org/10.1177/00221465211009202

Yuan, H., & Robert, J. V. (2021). Uncertainty in the COVID-19 pandemic and the art of medicine. *Pediatrics, 147*(5), Article e2020042937. https://doi.org/10.1542/peds.2020-04293

Ziebland, S., & McPherson, A. (2006). Making sense of qualitative data analysis: An introduction with illustrations from DIPEx (personal experiences of health and illness). *Medical Education, 40*(5), 405–414. https://doi.org/10.1111/j.1365-2929.2006.02467.x

Zinn, J. O. (2021). Introduction: Towards a sociology of pandemics. *Current Sociology, 69* (4), 435–452. https://doi.org/10.1177/0011392121102077