

## ORIGINAL ARTICLE

# ‘Don’t think that we die from AIDS’: Invisibilised uncertainty and global transgender health

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**Funding information**

National Science Foundation Graduate Research Fellowship, Grant/Award Number: DGE-1247312; Boston University Sociology Department Morris Funds; Boston University Graduate School; William & Mary Summer Research Grant

**Abstract**

The invisibilisation of social groups in health research and survey data is a source of medical uncertainty, long seen as a hallmark of the medical field. However, scholarship has not thoroughly assessed how medical uncertainty is structured by state-level processes and global health agendas, especially for people beyond the Global North. This article introduces *invisibilised uncertainty* as a type of medical uncertainty structured by global organisational and state-level priorities, which can invisibilise social groups and health problems from research and data collection, exacerbating medical uncertainty and health disparities for people worldwide. Based on 14 months of fieldwork in Thailand and in-depth interviews with 62 participants, the article illuminates how state-level processes and global clinical research agendas have structured knowledge gaps and uncertainties for Thai transgender women. As omissions in health research and data collection become embodied on a world scale, the article expands our understandings of how gendered health disparities are structured nationally and globally. It advances a sociology of medical ignorance by analysing the uneven landscape of holistic

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transgender health research, parsing how institutional dynamics can prioritise or invisibilise people and health issues in research and data, and structure uncertainties.

#### KEYWORDS

clinical research, gender, global health, medical uncertainty, Thailand, transgender health

## INTRODUCTION

To represent is to narrate, or to refuse to narrate. It is to perform, or to refuse to perform, a world of spatial assumptions populated by subjects and objects. To represent thus renders other possibilities impossible, unimaginable. It is, in other words, to perform a politics. A politics of ontology.

(Law & Benschop, 1997, p. 158)

Scientific and medical knowledge represent and act upon people—as well as ignore and make invisible. Social relationships and power differentials are embedded in census data, population health and clinical research worldwide (Adams, 2016; Bakhtiari & Sohoni, 2021; Beckfield, 2018; Casper & Moore, 2009; Epstein, 1995, 2008; Hanssmann, 2020; Krieger, 2012; Lawrence & Hirsch, 2020). The invisibilisation of certain social groups in health research has been pinpointed as a source of medical uncertainty (Almeling, 2020; Bird & Rieker, 2008; Shim, 2014), which has long been seen as a hallmark of the medical field (Fox, 1959; Light, 1979). Medical uncertainty emerges from a lack of technical information about clinical health issues (Kim & Lee, 2018), and conceptual taxonomies have illuminated different types, sources and manifestations of uncertainty to better understand their varied dimensions and effects (Han et al., 2011). Yet research on medical uncertainty is largely focussed on cases in the Global North and has not thoroughly accounted for how state-level and global institutional processes may define, prioritise or invisibilise populations and their health issues in research—while also controlling resources and setting health agendas for people worldwide (Birn et al., 2017; Büyüm et al., 2020; Vijayakumar, 2021). How is medical uncertainty structured by global organisational priorities and state-level processes? And how do people worldwide navigate and resist medical uncertainty, particularly when the lack of research is especially pronounced?

This article extends scholarship on medical uncertainty by exploring the structural processes through which global organisations and state-level institutions craft health research agendas and collect data, and in doing so, invisibilise certain social groups and health issues from questions asked. Incompleteness of medical knowledge can stem from the distinct ‘concerns, methods, and activities of researchers’ (Han et al., 2011, p. 6), while ‘research-based uncertainty’ manifests partially because economic incentives and funding mechanisms can compromise comprehensive quality medical research (Timmermans & Angell, 2001, p. 349). Meanwhile, global ‘problem choice’ is the creation, definition, categorisation and pursuit of certain issues, specifically within a largely unequal global health field comprised of many Global North-based institutions with particular aims and deliverables (Greene et al., 2013, p. 34; see also Ziman, 1987). Of these priorities is the HIV epidemic, which has been a large focus of global health organisations, sometimes to the exclusion or deprioritisation of other health and disease

burdens (Benton & Sangaramoorthy, 2021; Vijayakumar, 2021). Yet, less work has analysed how global problem choice and state-level processes foster gaps in holistic health research and data collection, exacerbating medical uncertainty for people across various social identities and geopolitical locations.

I introduce *invisibilised uncertainty* as a type of medical uncertainty structured by global and national health research agendas and monitoring, which can invisibilise health issues and social groups—such as transgender people, refugees, prisoners, immigrants, people with disabilities and stateless people—from data collection and policy. Based on 14 months of fieldwork in Thailand and in-depth interviews with 62 participants, the article analyses how Thai transgender women are largely invisibilised in data surveillance and holistic clinical health research, particularly as global and national health organisations focus on Thai transgender health largely in relation to HIV. Facing pronounced gaps in knowledge about other health concerns, Thai transgender women experience invisibilised uncertainty navigating health care most broadly, and when accessing gender-affirming services, including hormones and surgeries. They resist such globally and nationally constructed uncertainty by sharing advice and anecdotal information with each other both in person and virtually, mobilising to fill gaps in clinical evidence.

The article highlights unequal global representation in clinical research (Lawrence & Hirsch, 2020) by analysing the uneven landscape of global holistic transgender health research, underscoring implications for knowledge production and global health equity (Büyüm et al., 2020). It furnishes new micro and macro understandings of medical uncertainty in non-U.S. settings, demonstrating the ‘distinct interconnections and global processes that reshape health and health care in various parts of the world’ (Farber & Harris, 2022, p. 17; see also Bell & Figert, 2012). The article thus answers calls to ‘pars[e] distinct types of medical unknowns’, advancing a sociology of medical ignorance, of which medical uncertainty is a subcategory (Whooley & Barker, 2021, p. 280). It advances relational theories of gender and health by illuminating the ‘social processes that shape bodies’ (Connell, 2012, p. 1678), as omissions in health research and data collection become embodied on a world scale. The article expands our understandings of transgender health and policy (Hsieh & shuster, 2021; Newman et al., 2021; Reisner et al., 2021) by analysing global gaps in health research, pinpointing how global organisational priorities can ‘enable certain kinds of medical practices while impeding others’ (Adams, 2016, p. 225), and potentiate medical uncertainty. Despite the importance of HIV research, the article highlights how limitations in holistic transgender health research constrain broader evidence-based medicine, clinical guidelines and evidence-based health policy worldwide.

## MEDICAL UNCERTAINTY AND GLOBAL TRANSGENDER HEALTH

Who counts as part of a population and becomes integrated into the ‘public’ of public health is steeped in political, economic and social factors (Krieger, 2012). For instance, the exclusion of ‘invisible infertile’ groups, such as queer people, from reproductive health surveillance in the United States impacted their health-care access and health outcomes (Barnes & Fledderjohann, 2020, p. 4). Health research and broader census data often assume binary categories of cisgender men and women, eliding the existences and erasing the experiences of transgender and gender non-conforming people worldwide (Connell, 2021; Hanssmann, 2020; Reisner et al., 2016; Restar & Operario, 2019; shuster, 2021). Transgender health and medicine is characterised by uncertainty in medical decision-making and a lack of standardised data and guidelines (Dahlen et al., 2021; Reisner et al., 2016; shuster, 2019, p. 192). While trans people have

themselves amassed and shared a great deal of knowledge and evidence about gender-affirming health services (Aizura, 2018), recent work has analysed the specificities of uncertainty for transgender people and health-care providers in the United States (shuster, 2016, 2019, 2021) and United Kingdom (Pearce, 2018).

Currently, global transgender health guidelines from the Worldwide Professional Association of Transgender Health (WPATH) and Endocrine Society do not yet meet the Oxford Centre for Evidence-Based Medicine's system for evaluating evidence (shuster, 2016, p. 320). Global transgender health guidelines are largely based on research and clinical trials that are mostly conducted in the Global North (Dahlen et al., 2021; Reisner et al., 2016; Sweileh, 2018), reflecting broader trends that people from low- and middle-income countries—and their relevant health issues—are vastly underrepresented in clinical research (Lawrence & Hirsch, 2020). As a result of limited global transgender health research, international transgender health guidelines may not fully account for environmental, biological, political and cultural specificities of gender-diverse people in various contexts, nor the specificities of national health-care systems (Aizura, 2018; Dahlen et al., 2021; Höhne & Klein, 2019; Koehler et al., 2021; Winter, 2009a, 2009b; Winter et al., 2016). For instance, oestrogen patches might not adhere to the skin as well in hot and humid tropical settings, such as Thailand (Mamoojee et al., 2017, p. 244). What institutional mechanisms structure the pronounced gaps in transgender health research and evidence-based guidelines worldwide?

Global institutions in the HIV sector have constructed meanings of transgender identities and transgender health through programming, impacting material realities and community categorisations (Dutta & Roy, 2014, p. 327; Vijayakumar, 2021). HIV funding is an institutional 'catalyst' of transgender health research, mostly for transgender women (Reisner et al., 2021, p. 2), who are considered a 'key population', with a 13 times higher risk of contracting HIV than the rest of the population (UNAIDS, 2021). This undoubtedly warrants attention and resources. With transgender women worldwide disproportionately impacted by HIV, 75% of global epidemiological studies about transgender people's sexual/reproductive health outcomes pertained to HIV and STI prevalence (Reisner et al., 2016, p. 427). The HIV/STI focus means that 'other sexual and reproductive health concerns receive little attention', including fertility or pregnancy (Reisner et al., 2016, p. 427). For trans men in Peru, the 'critical gap in basic knowledge' about their health is structured by a lack of HIV funding for trans men, demonstrating how basic rights to health and health information are bound up in global organisational agendas (Reisner et al., 2021, p. 15). Recognising the necessity of HIV care, health researchers have still found it 'puzzling' that robust evidence and guidelines about transgender health are lacking in other important topics—such as chronic diseases, substance use and health behaviours; they suggest that the 'narrow' HIV focus may be 'driven by provider-interests rather than health care needs' (Dahlen et al., 2021, p. 8).

Comprehensive global transgender health research is a form of 'undone science' (Frickel et al., 2010; see also Hanssmann, 2020, p. 3), in which research topics go 'unfunded or are ignored' (Whooley & Barker, 2021, p. 279). As global funders, agencies and researchers have focussed on HIV often to the exclusion of other issues (Vijayakumar, 2021), many transgender health issues are deprioritised or disregarded. These include state violence, primary care, mental health, cancer and cardiovascular disease (Dahlen et al., 2021; Dutra et al., 2019; Hanssmann, 2020; Newman et al., 2021; Thomas et al., 2017; Vijayakumar, 2021). Beyond HIV, and beyond transition-related care, transgender people in many parts of the world have mobilised to address economic exclusion, criminalisation and other social issues (Vijayakumar, 2021), facing 'urgent health priorities', such as health-care discrimination (Thomas et al., 2017, p. 154). States also specifically enact violence by excluding transgender people from larger population

data. Trans health activists in Argentina, for example, have mobilised through 'statistical collectivism' to advocate for resources and create more accurate life expectancy rates for transgender women, which they estimate is 35 (Hanssmann, 2020). Global movements that archive worldwide violence, such as the Trans Murder Monitoring project, demonstrate the politicisation of death and uncounted data (Snorton & Haritaworn, 2013). How do HIV-centric global health research agendas, alongside national gaps in trans-inclusive health surveillance and policy, structure medical uncertainty and disparate health outcomes for people worldwide?

As most global trans health research deals with HIV (Sweileh, 2018), a lack of holistic global transgender health research delimits the creation of strong evidence-based medicine, which requires funding and resources to create—and can further stratify those who are excluded from such data (Broom & Adams, 2016, p. 13). More broadly, ambiguity regarding health issues arises due to the 'reliability, credibility, or adequacy' of existing conflicting or incomplete risk information (Han et al., 2011, p. 5). Yet when social groups and their distinct health issues are invisibilised in health research and data collection, risk information might not exist at all. This is a form of meta-ignorance, or a lack of knowledge about what is unknown (Han et al., 2011). So far, scarce research has examined how medical uncertainty might be structured worldwide by global organisational and state-level gaps in health research, which can invisibilise certain social groups and constrain the questions asked about health.

Invisibilised uncertainty bridges an attention to macro-level processes (e.g., global clinical research agendas and state-level priorities) with micro-level health outcomes and interactions. The concept situates medical uncertainty beyond the 'relational act' between health-care providers and people receiving care (Han et al., 2011, p. 10), showing how global organisational and state-level activities can structure and delimit who is included in health research—and what problems are predominantly asked, funded and prioritised (Adams, 2016; Casper & Moore, 2009; Oni-Orisan, 2016; Shim, 2014; van de Ruit, 2019). The article elucidates how 'undone science' (Frickel et al., 2010) manifests in undone clinical guidelines, undone health policy and invisibilised uncertainty. To be clear, invisibilised uncertainty and the impending health disparities are in no way invisible. Rather, it is the vast array of health problems, research questions and social groups that remains largely invisible to the eyes of global health funding organisations and state-level institutions.

## TRANSGENDER HEALTH IN THAILAND

Although Thailand is hailed as the 'Land of Smiles', and state agencies promote the country as an LGBTQ-friendly destination for tourists, Thai transgender people face discrimination in a variety of settings, including employment, schools and health-care systems (Farber, 2022; Pramoj Na Ayutthaya, 2007). Some Thai transgender people reported receiving medical services in hallways because there are only male and female wards and have been refused care altogether (Farber, 2022). Thailand is a global model for universal health coverage (Harris, 2017), but national health insurance does not yet cover gender-affirming services, such as hormone treatments, even though gender-affirming services are a social determinant of health for those who want them. Thailand is also a global leader in HIV prevention and treatment, as the government integrated antiretrovirals under its universal health coverage programme (Harris, 2017).

Although around 91.7% of Thailand's HIV response in 2019 was funded by domestic organisations (Viriyathorn et al., 2021), international donors—such as USAID, PEPFAR, and the Global Fund to Fight AIDS, Tuberculosis and Malaria—support HIV prevention for 'key populations',

including transgender women. Thai transgender people have an HIV prevalence of 11% (UNAIDS, 2020), and international HIV and AIDS funding brings vital resources to Thailand, such as helping catalyse several Thai community-based clinics that offer not just HIV services but also ‘wrap-around’ transgender health care, such as hormone monitoring. In these settings, HIV is not ‘mounted in isolation’ (Whiteside & Smith, 2009, p. 5), and Thai trans women exert notable agency (Lynne & Enteen, 2021).

Despite the government’s leadership in addressing HIV (Viriyaathorn et al., 2021) and the country’s gains in internationally funded transgender health care, this article shows how a paucity of holistic clinical research, guidelines and trans-inclusive health policy undergirds medical uncertainties for Thai trans women and their health-care providers. In what follows, I describe the methods used. I then analyse how invisibilised uncertainty is structured by state-level processes and health research agendas, as well as global clinical research that focuses on transgender health largely in relation to HIV. Amid such structural invisibilisation, I then discuss how Thai transgender women experience invisibilised uncertainty with gender-affirming surgeries and hormones. I conclude with a discussion of the findings and implications.

## METHODS

This article is based on in-depth interviews with 62 participants conducted from 2016 to 2021 and 14 months of fieldwork in Thailand, conducted in 2016 and 2017–2018. Global ethnographic research integrates an attention to macro political–economic social structures and everyday lived experiences (Hoang, 2015). The fieldwork took place in the Bangkok metropolitan area, Nonthaburi, Phuket and Pattaya, which are places where many Thai transgender women live and work. One interview was via email, and six interviews (including follow-ups with key informants) took place via video conference. As part of a broader project about Thai transgender women’s health outcomes amid the state-led growth of medical tourism, the interviews included 36 Thai transgender women, six health-care professionals, six officials from the Ministry of Public Health, four civil society members, three owners involved in the transgender entertainment industry, two medical tourism stakeholders, two private hospital CEOs, one official from the Tourism Authority of Thailand, one medical tourist and one representative from a United Nations-related agency.

The average age of Thai transgender women in the sample was 27 years. Three had earned their Master’s degrees, ten had earned their Bachelor’s degrees, seven were university students, ten were high school graduates, two were middle school graduates and four did not report their educational background. With 36% of this sample earning a Bachelor’s degree or above, this is higher than the broader population, of which 15.63% had earned at least a Bachelor’s degree in 2019 (UNESCO Institute for Statistics, 2019)—although the latter percentage is only based on binary categorisations of men and women. Twenty-four Thai transgender women in the sample worked full time jobs, and the average income for those working full-time was \$550 USD, which was at the time \$300 less than the average monthly income in Thailand.

I gained fundamental proficiency in Thai and was assisted by Thai translators in 33 interviews with Thai-speaking transgender women. Translators were familiar with the specificities of sex, gender and sexuality in Thailand, and they transcribed the interviews conducted in Thai. As I was not fluent in Thai, I was limited in my everyday conversations and relied on outside research assistance to integrate information from Thai newspapers, Facebook groups and other materials. Thai transgender women were recruited through a health clinic and snowball sampling, as participants referred me to other potential interviewees to diversify the sample. Following the norms

of the health clinic, Thai transgender women were compensated monetarily for each interview. All interviews were recorded for accuracy and edited slightly for grammar and coherence, and coded for themes in NVivo. I use pseudonymous nicknames rather than full first names to stay consistent with Thai cultural norms.

During fieldwork, I observed public and private hospitals and clinics and spent time with Thai transgender women at their workplaces. I analysed materials published by transgender rights organisations nationally, regionally and globally. I attended several LGBTQ activism events in Bangkok and regional meetings related to transgender health and social rights. These meetings had representatives from community-based organisations, national and regional non-governmental organisations (NGOs) and international organisations. The first was a three-day dialog sponsored by the United States Agency for International Development (USAID), international nonprofit FHI 360, United Nations Development Programme (UNDP) and Joint United Nations Programme on HIV/AIDS (UNAIDS) to leverage expertise in helping countries reach the UNAIDS' '90-90-90 targets'. The 90-90-90 campaign aims that 90% of people who are HIV-positive know their status; 90% of those are on treatment and 90% have their viral loads suppressed. One-hundred and fifty delegates from 20 countries in Asia gathered to discuss transgender health issues and strategies. The meeting culminated in a 'preliminary regional mapping report' that delineated the specific issues of transgender people in Asian countries, including trans competent services, hormone use, surgeries, HIV and insurance.

The second 4-day meeting was sponsored by the Asia Pacific Coalition on Male Sexual Health (APCOM), which was held in connection with the UN's Sustainable Development Goals (SDGs) and the UNAIDS 90-90-90 targets. It included sessions about HIV treatment implementation and social rights orbiting around sexuality and gender identity. While many of the topics included aspects of transgender health, that the meeting specifically addressed 'male sexual health' demonstrates how populations appear, or are collapsed together, under global organisational categories (e.g., men who have sex with men or MSM), reflecting the transnational transformations of these 'biologized understandings of maleness' (Boellstorff, 2011, p. 296). The necessary distinction between transgender women and MSM categorisation has occurred only recently (Lynne & Enteen, 2021, p. 1).

Lastly, the Global Fund Advocates Network-Asia Pacific (GFAN-AP) collaborated with the Asia Pacific Council of AIDS Service Organizations (APCASO), a regional civil society network of community-based organizations (CBOs) and NGOs, focussing on HIV, health and social rights to host a forum on Universal Health Coverage (UHC). Under the Strategic Framework of the Global Fund 2017–2022 and SDGs, especially Target 3.8 on UHC, the caucus was held to allow stakeholders to address planning, gaps, messages and activities related to UHC, particularly for 'key populations'.

I also analysed all current and completed clinical trials in Thailand, using 'transgender' as a search term in databases on [ClinicalTrials.gov](https://clinicaltrials.gov), the International Clinical Trials Registry Platform, and the Thai Clinical Trials Registry. I categorised each study according to the topic (e.g., HIV or depression) and noted primary and secondary research sponsors and collaborators.

I align with other scholars intent on mitigating power relations embedded in research from the Global North (Connell, 2021), as well as research focussing on transgender people exclusively (Vidal-Ortiz, 2008). To incorporate everyday complexities (Connell, 2006), I involved participants in every stage of the research, such as creating interview guides in consultation with transgender people themselves and transgender health practitioners/activists. When quoting participants, I refer to each person using the terminology they used to self-identify. Some participants identified as '*sao praphet song*', which translates to 'second kind of woman'. Others found this word

offensive, stating it denoted they were second-class citizens. To avoid referring to participants as an identity category deemed offensive, I refer to participants as a whole as Thai transgender women and recognise the imperfections of this categorisation (Aizura, 2018; Dutta & Roy, 2014; Hanssmann, 2020).

The research was approved by Institutional Review Boards in the United States and Thailand.

## Structuring invisibilised uncertainty

Twenty-three out of thirty-two (71.88%) current or completed clinical trials about transgender health in Thailand were related to HIV. Of the 23 clinical trials pertaining to HIV, all but two (91.3%) were conducted, sponsored or partially sponsored by international organisations, pharmaceutical companies or Thai organisations that receive international funding. Currently, the Ministry of Public Health (MOPH) is a sponsor, collaborator or listed as a contact for four clinical studies related to transgender health, all of which focus on HIV. In this context, participants acknowledged how stereotypes about HIV and AIDS are embedded in society. Naw, who identifies as *sao prophet song*, stated: 'Don't think that we die from AIDS. We can die by getting hit by cars and other diseases'. Naw highlights stigma and global problem choice, which focuses on certain health and disease burdens and not others. In conjunction with the internationally funded and HIV-related transgender health agenda, invisibilised uncertainty is also structured at the state level by the invisibilisation of transgender people from official censuses and monitoring.

Thai transgender people cannot change their legal identification cards to reflect their genders, and this can create barriers not only to health-care access (as participants stated that it can be humiliating to be publicly misgendered in health-care settings) but also to data collection and health surveillance. According to Bee, a *sao prophet song*: 'I want the state to give us rights and see me as a woman'. Thai trans women remarked that their lack of legal recognition impacted their daily lives. Unseen at the fundamental level of gender recognition in legal documents and invisibilised on a sex/gender binary in official censuses, Thai trans people have also been invisibilised in national health research agendas and public health-care settings.

According to Mon, a Ministry of Public Health (MOPH) official, holistic transgender health research has not thoroughly been addressed at the state level. Mon said: 'The question [of how to prioritise Thai transgender health] remains unanswered because we need to set up a research design... It's a delicate issue, but I don't know what is to be done on this'. As Mon explicates her own uncertainty about how to craft a trans-inclusive health research agenda, other MOPH officials did not see transgender people as needing 'special attention'. In discussing the feasibility of expanding universal health coverage to include gender-affirming services, MOPH official Dr. Wirat remarked:

I think sometimes the public thinks we already provide sufficient things for [transgender people]. For example... they can express themselves freely in public... We accept them as a Thai citizen. They should get rights in access to health services as a Thai citizen. But if we think they are a special group or they are vulnerable – so perhaps they need more services, they need special attention, they need special treatment from the government or from the public – perhaps I think this kind of request or requirement, perhaps, is too much. You know what I mean? It's too much for the public to accept this proposal.

(Dr. Wirat)



Dr. Wirat reflects his view that the public would not approve of giving 'special attention' and 'special treatment' to transgender people, stating that trans people's right to exist in public is 'sufficient'. While transgender people should not be categorised as an 'inherently vulnerable population', they are broadly a group 'facing sex and gender related situated vulnerabilities for different health conditions' (Reisner et al., 2016, p. 430). Yet the structural vulnerabilities experienced by many Thai transgender people remain largely invisible to health policymakers, as Patcharin, a founding member of the Thai LGBT rights movement, stated that Thai trans people are 'not taken notice [of]' in health-care settings. She remarked:

I think the health institutions that are responsible for the overall health of people have not taken notice [of transgender people's needs], and haven't done their job in providing necessary information for people to care for themselves, or to make a good choice on medical services—whether what kind of contraceptive pills they should take, what kind of hormones or how they should take it, or what these surgeries mean and how to equip them in making their choices to get these services.

(Patcharin)

Patcharin underscores what she calls a 'grey zone' of missing health information about a range of Thai transgender health issues, as basic health information remains inaccessible and clinical protocols are undone.

Invisibilised uncertainty is produced as the majority of clinical trans health research in Thailand, which is mostly connected to international funders, focuses on HIV. Thai transgender people's existences are not counted in official monitoring, as they lack legal gender recognition. As trans people are not seen by MOPH policymakers as needing 'special attention', neither public health research agendas nor health policies have fully incorporated trans people and their health needs. According to Patcharin, trans people face a 'grey zone' of missing health information and are not 'taken notice' of in health-care settings. All of this structural invisibilisation—occurring nationally and globally—exacerbates medical uncertainty, resulting in the invisibilised uncertainty described in the next sections.

## Invisibilised uncertainty with surgeries

Thai transgender women experience invisibilised uncertainty navigating health care and surgeries without accessible medical advice or clear protocols, often encountering risks and responsibilities without institutional support (see also Almeling, 2020, p. 138). They face uncertainty regarding the quality of doctors and clinics offering surgeries, while medical providers experience uncertainty with decision-making, sometimes lacking expertise in surgical after-care.

Bim, a *sao prophet song*, shared what she believes is the biggest health problem for Thai transgender people: navigating gaps in standardised health information about gender-affirming surgeries. According to Bim: 'I think the most serious problem for Thai transgender people... is surgery. Because sometimes we get inadequate information. Sometimes we go see doctors, and we don't know if this doctor is good or not'. Bim addresses the barriers in accessing health information about surgeries and uncertainty about the quality of doctors, reflecting larger gaps in standardised trans-inclusive medical training (Hana et al., 2021). Goldie, who did not want to use an identity category, encountered a clinic that did not provide information about what to expect after her gender-affirming surgeries. Without health protocols that required a proper overview,

Goldie said: 'We just go and do the surgery'. San, who identifies as *sao praphet song*, also navigated health and surgical information without the help or guidance of health professionals. San remarked: 'I did my own research... I also relied on comments from [clinic] clients...' Bim, Goldie and San all emphasised the lack of information and protocols about surgeries, facing uncertainty about the quality of medical providers who were not always trained in transgender health.

As medical providers grapple with the 'little scientific evidence' of trans medicine, providers may take a gatekeeping role, rely on binary norms to determine candidacy for gender-affirming surgeries, and expect patients to be completely certain about interventions (shuster, 2016, p. 321). Exemplifying these trends, Dr. Arun, a surgeon, remarked:

I think we have to choose the right [candidate for surgery] carefully. Sex is something complicated... You have to find the right person who *really* wants to change from man to female – [who] most really wants to be a female. That's a good candidate for surgery. In between: I'm not so sure... I have to have a good feeling they are a good candidate because I'm the one doing the surgery... If I feel it's not the right candidate, I tell you that you should spend more time and get real life experience as a woman. Dress like a woman, go out and see what you feel like. You have to show up as you are female. Go out and have real experiences dressing as a woman, showing up like a woman, and come back to see me. There's something else you can do. You can have breast augmentation. This is a reversible procedure. Look like a female and [see if you] are happy with that...

(Dr. Arun)

Dr. Arun deals with uncertainty by underscoring his authority, asserting his role as 'the one doing the surgery', and reifying binary norms about sex and gender, such as what it looks like to 'show up as you are female'. Dr. Arun manages what he deemed 'complicated' clinical decision-making by focussing on 'real life' experiences, solidifying patterns of health-care providers asking transgender people to prove their authenticity through outward appearances (Aizura, 2018; Johnson, 2019; Pearce, 2018; shuster, 2021), as well as demonstrating health-care bias towards gender conformity (Hana et al., 2021). Dr. Arun's reliance on a 'good feeling' about surgical candidacy reflects themes about how transgender health specialists in the United States have likened their medical judgement with trans patients to a kind of 'Spidey sense' (shuster, 2021, p. 1).

In addition, health-care providers may have less clinical expertise and competency caring for trans patients who have had surgeries, demonstrating global trends in limited trans-inclusive medical education (Hana et al., 2021). Dr. Wanida, who specialises in transgender health, said that most doctors are not trained to provide short- or long-term care for surgically constructed neovaginas. With 20% of the clinic's patients undergoing these surgeries, she said this was a significant issue for them. Riki, an LGBTQ health advocate, echoed that there is a gap in standardised follow-up transgender health care: 'In terms of gender surgeries, the health care providers prefer that you don't come back for long-term care. Doctors don't have any idea of how to do that'.

Limited comprehensive transgender health research beyond questions of HIV structures the limited guidelines and protocols regarding gender-affirming services, such as surgeries. Dr. Arun's subjective clinical decision-making coincides with a medical model that is constrained by a lack of holistic, culturally specific evidence. Thai transgender women rely on their own research and social networks for proper surgical information and follow-up care. I now discuss how invisibilised uncertainty manifests regarding hormone use.

## Invisibilised uncertainty with hormones

In Thailand, hormones are widely available without a prescription in pharmacies; this access contrasts with the lack of global clinical knowledge about hormone use (Humphries-Waa, 2014). Most research about the long-term effects of hormone regimens has taken place in Europe (Deutsch et al., 2016, p. 1101), while most Thai clinical studies about transgender health and hormones were internationally funded studies dealing with HIV prevention and treatment. Credible guidelines about hormone use in different country contexts must be based on empirical research, which is currently lacking on Thai transgender people, who might have lower body masses and therefore need less medication, according to Dr. Wanida. To adapt international guidelines for the specificities of Thai transgender people, Jaya, who is an LGBTQ advocate in an NGO and preferred no label, stated that more clinical evidence is needed. She said: 'We need to have rigid research that this [hormone] medicine can apply to us'. Without Thai-inclusive clinical research, Jaya and Dr. Wanida both emphasised the difficulty in guideline creation for hormone monitoring in the Thai context.

With over-the-counter hormone availability, clinical knowledge gaps and a dominant clinical research focus on HIV, all Thai transgender women interviewed had hormones recommended by friends or family, not doctors, and many expressed concerns about the unknown health risks and long-term effects that hormones might cause. Naw, a *sao prophet song*, said she began taking hormones when she was around 12 years old after a close neighbour introduced them to her, but she did not know the physical effects they would have on her. Without hormone counselling, Naw believed it was her personal responsibility to learn more about medical effects of hormones, rather than for medical providers to share clinical information. Naw said: 'We have no knowledge on hormones, like which hormone suits me best'. Naw emphasised the absence of medical expertise and clinical knowledge about hormones.

Evy remarked that she had difficulty finding a specialist who understood hormone treatment for transgender people. She said: 'Most of the doctors in endocrinology don't know about hormone treatment. Even endocrinology doctors don't know'. Emphasising that specialists lack this trans-inclusive knowledge, Evy went on to say that there is limited knowledge about hormones, among only a handful of doctors. She added: 'So few doctors in Thailand—I think I can count no more than five—know about this to help us'. With limited medical guidance and knowledge on hormones, Evy also pointed out that while Thai transgender people must have hormone treatment before they qualify for gender surgeries, 'they don't have doctors to support us', in terms of choosing and maintaining a healthy hormone regimen. Evy noted how Thai trans women lack standardized treatment in the absence of larger guidelines. She continued: 'Maybe some doctor recommends you use hormones like this, like this, like this, but another doctor doesn't have a standard for treatment... One doctor says something, another doctor has another way'. Evy spoke to a lack of uniform standards and guidelines, which might also differ if a provider is affiliated with a professional organisation (shuster, 2019, p. 194).

Several Thai transgender women stated that they were worried about the long-term effects of hormones, with family members also expressing concern. Nin, who preferred no label, said: 'I think we need to deeply consider our health and aftermath [of hormones]. When I was 20-something years old, I used a lot of hormones. But now that I am 30, I feel that my health condition is not too good. And I fear that it might even get worse in the future. Like, I will become sick easily, or feel that my bones are increasingly weaker, because I feel muscle pain easily'. Other respondents discussed the unknown effects on their organs and family disapproval due to health concerns. Oom, a *sao prophet song*, said: 'My family never encouraged me to take too many

hormones, because it will make my kidneys work too hard and might cause long-term consequences'. With Thai trans women accepting the unknown risks of self-administered hormone use, they also remarked that medical concern for them is sometimes absent. Evy said: 'Maybe the doctors worry about health risks, but some doctors don't [show] concern... So transgender people know about the risks, the adverse effects—we know, but we still take the risks because we need to be feminine'. Nin and Evy spoke to their risk assessment and decision-making amid invisibilised uncertainty, while also demonstrating how trans people can have 'little confidence' in the medical establishment's expertise about hormones (Gooren et al., 2013, p. 283).

Without formal medical oversight, Kittii, who preferred no label, said that health information from a Facebook page taught her how to take oral contraceptives and inject hormones. In the absence of clinical, the online assistance demonstrates the convergence of physical and virtual spaces, as identities, embodiment and health outcomes are impacted through online spaces and interactions (Kempner & Bailey, 2019). With the lack of broadscale clinical research about hormones in the Thai context, invisibilised uncertainty is compounded by the hyper-availability of self-prescribed hormones, without standardised oversight and monitoring.

## CONCLUSION

As medical uncertainty emerges from a lack of technical information about clinical health issues (Kim & Lee, 2018), invisibilised uncertainty results from the structural invisibilisation of social groups and health issues from global organisational and state-level research agendas, as well as data collection and health policies. With most clinical research conducted in high-income countries and seven to eight times more likely to focus on issues relevant to those settings (Lawrence & Hirsch, 2020), the dominant focus of global transgender health research in relation to HIV limits holistic clinical evidence and guidelines about other important topics—such as mental health, discrimination, state violence, primary care, reproductive health, hormones and surgeries. Global problem choice not only prioritises certain people and problems (Greene et al., 2013), but also constrains holistic and inclusive clinical evidence, guidelines and health policy. This coincides with state-level processes, as Thai transgender people are unable to change their gender markers on identification cards and are invisibilised in official monitoring, and trans-inclusive health research agendas and policies remain largely undone.

For Thai transgender women, invisibilisation in official monitoring and holistic health research beyond questions of HIV structures the 'grey zone' of limited health information *and* undone clinical protocols regarding hormone use, surgeries and general medicine. Gender-affirming surgeries are sometimes offered with little health information, standardisation or follow-up care for patients. Dr. Arun's notion of who 'really' wants to transition—and what it means to 'get real life experience as a woman' is not just an example of the micro-level negotiations that take place between providers and transgender people (Johnson, 2019); his reliance on a 'good feeling' is also structured by limited evidence-based medicine, itself hinged on narrow national and global health research agendas that then restrict culturally specific clinical guidelines.

In addition to navigating surgeries without information or guidelines, invisibilised uncertainty manifests with regard to unestablished research and protocols on hormones. Although scholarship has shown how the diffusion of new health technologies is not always equal—such as in cases of expensive statin drugs (Chang & Lauderdale, 2009) or infertility treatments (Barnes & Fledderjohann, 2020)—there also arise distinct uncertainties and disparities amid widespread, unregulated availability and limited contextualised research. The findings add to

our understanding of technology diffusion and health outcomes in different country settings, as clinical oversight and longitudinal research are lacking.

With gaps in clinical health research much beyond HIV, Thai transgender women resist invisibilised uncertainty by mobilising through in-person and virtual social networks, creating their own anecdotal data in everyday life. In conjunction with NGOs and grassroots organisations (Lynne & Enteen, 2021), they also serve as key nodes of knowledge production, as 'lay' individuals who mobilise to counter missing clinical data, expanding the concepts of 'expertise' and 'knowledge' to incorporate their own crucial experiential data (Brown et al., 2003; Epstein, 1995; Shim, 2014, p. 206). Thai transgender women make surgical health decisions based on guidance from peers—a form of 'collective work' (Connell, 2021, p. 91)—rather than receiving personalised treatment from medical providers. Through their lived experiences and sharing of information, they answer questions not yet addressed by global organisations and national health institutions. National, regional and global NGOs have created new blueprints for transgender health and medicine in Asia, such as the Thai Handbook of Transgender Healthcare Services, a multidisciplinary and holistic resource published in 2021. Future research can assess how such a guidebook might alleviate invisibilised uncertainty, improve transgender health outcomes and possibly serve as a model diffused to other country settings.

While medical uncertainty is the expected 'norm' in the vast field of medicine (Mun, 2020), it can be mitigated with standardised data collection and health/disease monitoring, which are core features of health equity and resource distribution (Reisner et al., 2016). Census-type data collection invisibilises people beyond the sex/gender binary, delimiting general and specific understandings of transgender people's lived experiences. Ninety-five percent of health organisations do not include transgender populations in their definition of gender, and the 'near-universal exclusion' of transgender people from health paradigms perpetuates inequities (Restar et al., 2021, p. 2). The Institute for Health Metrics and Evaluation (IHME), a major source of global health data catalysed by the Bill and Melinda Gates Foundation, has published nothing to date on its website about transgender people's health anywhere in the world.

There is a need for new measurement technologies in social scientific research, surveys and broader data collection beyond binary sex and gender (Geist et al., 2017; Reisner et al., 2016). A 'two-step' identification method would allow people to report sex assigned at birth, as well as provide their self-identified gender based on regional, cultural and linguistic specificities (Reisner et al., 2016, p. 430). State institutions must support these goals, as data about people across spectrums of sex, gender and sexuality in Thailand is 'unlikely to be captured on a consistent and reliable basis in the absence of government support' (Newman et al., 2021, p. 15). What remains unstudied about transgender health worldwide leads not only to invisibilised uncertainty, but also constrains evidence-based public health-care policy (Lin, 2008). Transgender health organisations worldwide assert that transgender-inclusive universal health coverage, health-care education and training, and research and inclusion are necessary.

This article conceptualises invisibilised uncertainty as the medical uncertainty that arises amid national and global health research agendas, data collection, and policies that prioritise or invisibilise certain people and issues. By centering the global and national health research that has yet to take place, invisibilised uncertainty makes apparent the embodied and uncertain effects of health data gaps, analysing their structural origins and global consequences—so that scholars, policymakers and practitioners can better identify and address health issues about social groups decidedly left unknown.

## AUTHOR CONTRIBUTIONS

**Reya Farber:** Conceptualization (Lead); Data curation (Lead); Formal analysis (Lead); Funding acquisition (Lead); Investigation (Lead); Methodology (Lead); Project administration (Lead); Resources (Lead); Software (Lead); Supervision (Lead); Validation (Lead); Visualization (Lead); Writing—original draft (Lead); Writing—review & editing (Lead).

## ACKNOWLEDGEMENTS

My thanks to Elyas Bakhtiari, Diya Bose, Fernando Galeana Rodriguez, Jonah Goldwater, Amy Quark, Meaghan Stiman, Catherine van de Ruit, as well as two anonymous reviewers for their constructive feedback on this manuscript. Thank you to Cati Connell, Alya Guseva, Joseph Harris and Ashley Mears for their support and feedback on earlier drafts. My thanks to organisers and participants of a Medical Sociology paper session at the American Sociological Association 2022 conference. I am indebted to the research assistance of Gabriel Seuboon Chaiyasit, Suphakrit Jitrarat and Kevin Laddapong. This material is based upon work supported by a National Science Foundation Graduate Research Fellowship under Grant No. DGE-1247312, Boston University Graduate School, Boston University Sociology Department Morris Funds and William & Mary Summer Research Grant. Most sincere thanks to the participants who shared their time, thoughts and trust.

## DATA AVAILABILITY STATEMENT

Author elects to not share data.

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**How to cite this article:** Farber, R. (2022). 'Don't think that we die from AIDS': invisibilised uncertainty and global transgender health. *Sociology of Health & Illness*, 1–17. <https://doi.org/10.1111/1467-9566.13563>