The Epistemic Determinants of Health

EPIC: Epistemic Injustice in Healthcare

2025

Image: West Midlands (UK) Tuberculosis sanatoria and public information.
Heart of England NHS Foundation Trust.
Source: Wellcome Collection.

Contents

Summary

- Alongside crucial frameworks such as the legal, political, social, cultural, and commercial determinants of health, sustained attention is needed to the *epistemic* determinants of health: how the mechanisms and dynamics of gaining and sharing knowledge affect our health and relation to healthcare practitioners and institutions.

- Rethinking health and healthcare systems in epistemic terms opens up extensive opportunities for promoting knowledge and health justice, advancing understandings of healthcare interactions, how people engage with health care services, and the relationship between expertise by experience and medical/public health knowledge and practice.

- Using the notion of epistemic injustice to analyse and understand healthcare processes, concepts, and settings, this framework develops and evidences our contention that health and illness are significantly determined by access (and barriers) to knowledge and its successful (or failed) communication.

- This document offers an accessible and practical introduction to state-of-the-art research on how these problems play out in healthcare contexts and processes, which we illustrate with case studies from philosophy, history, law, psychiatry, medical humanities, and medicine.

- By attending closely to the intimate workings of knowledge and power, it offers new theoretical grounding for calls for ‘Patient and Public Involvement (PPI)’ and the co-creation of research with experts by experience, considering the conditions and dynamics of open, just, and ethical epistemic exchanges.

- This document is intended to open questions and conversations, not settle them. It is fully referenced, so readers can follow arguments and evidence back to their source, and includes biographies, areas of expertise, and contact details for the contributing authors. Further reading and resources are detailed towards the end.

- We welcome contact from anyone interested in working with us, or learning more about epistemic injustice and the project behind the report. You can read further – and get in touch – at https://epistemicinjusticeinhealthcare.org/.

How to cite this document: EPIC (Epistemic Injustice in Healthcare), The Epistemic Determinants of Health. Behavioural and Cultural Insights Hub (WHO/Europe, 2025). https://bci-hub.org/documents/epistemic-determinants-health.

Introduction

Health and illness are significantly determined by knowledge and its communication. At first glance, this might seem obvious; people use healthcare systems when they suspect that something might be wrong, a suspicion connected both with lived knowledge about and from their minds, bodies, and environments, and broader knowledge about how ill and healthy minds and bodies are supposed to feel and function. Likewise, the possibility for effective treatment depends – among other things – on what knowledge healthcare professionals have, whether that knowledge comes from the ill person directly, from their training or wider reading, or from the resources available to them in their profession (i.e., the sum of accessible knowledge about a particular condition or disease). The problem is that these considerations are rarely straightforward, vulnerable to considerable blocks, barriers, and failures, and structured by systemic injustices in the creation, communication, and reception of knowledge.[1]

As an interdisciplinary team of philosophers, psychiatrists, historians, and medical and legal scholars, our project is committed to better understanding, evidencing, and ameliorating a cluster of interrelated phenomena, within and around healthcare systems, referred to by Miranda Fricker as 'epistemic injustices'.[2] Attending to these dimensions – the *epistemic* dimensions – of health and healthcare, our work suggests, can offer a new perspective on, and pathway through, significant medical, ethical, and public health challenges today. But what do we mean by 'epistemic', and what do we mean by 'injustice'?

Epistemic practices are the things we do to acquire, share, assess, and use knowledge. They can be individual or collective, and they range from the very simple to the highly complex. Examples include: asking and answering questions, criticising an opinion, requesting and offering information, listening, investigating, exploring, researching, theorising, offering hypotheses, sharing one's beliefs and voicing objections.[3] Epistemic practices involve knowing, understanding, and other *epistemic goods* which are needed to manage our life and navigate the world, such as credibility (being believed).[4] Complex epistemic practices rely on social structures and institutional arrangements. Ideally, our ways of arranging the social world support efficient, equitable, and sustainable epistemic practices. In most cases, epistemic practices often do not meet these ideals.[5] Consider three examples of the 'non-ideal' realities of epistemic practice:

1. **Speaking**. In ideal cases, when people speak, they are given credibility and respect; this means that what they say is given 'uptake'. Unfortunately, prejudices and stereotypes may cause us to ignore what some people are saying. In other cases, people are listened to, but they are denied credibility and respect; or an institution's design or culture prevents people from speaking by only assigning speaking rights to certain privileged groups.
2. **Listening**. Good epistemic practice often involves listening to different groups of people to learn from their experiences, perspectives, and ways of thinking. Good listening enriches collective knowledge: everyone learns from everyone else. In many cases, however, various groups are ignored: the idea of learning from them is considered absurd. Alternatively, members of an oppressed group might be listened to, but only under limited conditions.[6]
3. **Questioning**. Social life requires asking questions – to make sense of the world, identify problems, and foster trust. This involves skills of good questioning and related skills of answering questions well. In reality, questions are often ignored or dismissed,

or the answers given fail to respond to the content of the question. Questions are also suppressed and asking questions about certain topics can involve serious risks.

These examples show the importance of good epistemic practices. They also highlight an important category of injustice: *epistemic injustice.* These are wrongs done to someone who faces unfair obstacles when trying to speak, listen, and question.[7] In healthcare, epistemic injustices have been identified as manifesting in two major ways:

1. Ill persons' reports are undervalued or dismissed because of tacit or explicit beliefs about their cognitive ability, social identity, extreme emotions leading to unreliability, or stigma around illness (e.g. that someone with dementia can tell us nothing of value). Such biases undermine their ability to communicate experiences, which is crucial for effective diagnosis and treatment. This is *testimonial injustice*.[8]
2. Individuals or communities lack the interpretive resources to articulate their health experiences, or their interpretations are prevented from receiving just uptake, often due to structural inequalities that limit opportunities to create or access knowledge of health, illness or healthcare systems. Dominant forms of knowledge can prevent members of marginalized groups from fully participating in healthcare decisions about their care or more broadly about policy. This is *hermeneutical injustice*.[9]

Both testimonial and hermeneutical injustice are shaped by social determinants, such as organizational culture and public policy; educational systems; economic arrangements; race, gender, or sex discrimination; and political ideologies. They have different effects:

1. they can impact the capacity of marginalized persons to access, gain, or share knowledge of their health or illness equitably;
2. they can impact the value or credibility given to testimonies and experiences, and thus the capacity to articulate health needs.[10]

Health systems play a crucial role in mitigating or amplifying such inequities within healthcare. Policies and norms that guide behaviour in healthcare play a critical role in shaping how knowledge about health is made and managed. Institutional logics, influenced by broader social and economic structures, shape interactions among healthcare actors and impact socio-cognitive processes involved in healthcare. Discriminatory epistemic practices within healthcare settings can exacerbate challenges faced by marginalized individuals and groups, reinforcing cycles of epistemic injustice.[11] Developing a better understanding of the social factors behind epistemic injustices in healthcare is essential for improving healthcare experiences. *Epistemically just* healthcare recognizes that remedying the devaluation of certain ways of understanding health and illness can improve both health outcomes and healthcare systems.[12]

This theoretical framing allows us to understand that problems of knowledge in health, illness, and medicine are frequently not accidental, but an expression (and perpetuator) of ingrained structural discrimination and moral failings in wider societies. Thus, a person might be unjustly prevented from understanding the seriousness of their symptoms by, for example, a two-tier educational system along lines of race or class, or an omission to provide effective translation for a public health campaign.[13] Another person may face significant problems communicating what they know about their own mind or body to their physician due to prejudices about the group they belong to, including their identity as an ill person. Still another could be constrained in their understanding of what is happening to them by unjust gaps in knowledge about their experience or by apposite knowledge about that experience being blocked from uptake in official (or wider public) narratives.[14]

An example of what we mean by the epistemic determinants of health can be found in recent research conducted by the Eve Appeal, a UK gynaecological cancers charity, into a 'knowledge gap' on cervical screening. Noting that 1 in 3 screening invitations for HPV weren't taken up in 2023 and 2024, they implicate a 'lack of knowledge of some steps and adaptations women and people with a cervix can ask for during their cervical screening appointment to make the appointment easier and more comfortable.'[15] To avoidance through anticipation of pain and discomfort we could also add shame, fear, embarrassment, and trauma; women who have suffered sexual assault, in particular, find the test difficult and frequently avoid it altogether.[16] Lack of knowledge about the likelihood and severity of cervical cancer also poses epistemic challenges. This particular campaign, though, aims specifically at equipping readers with the knowledge they need to control and personalize their screenings, empowering them to take a more active agential role. Of the people surveyed, 56% were unaware that they could stop their test at any stage, 77% didn't know that they could request a smaller speculum, only 12% knew that they could ask for a double appointment, and only 11% knew that they could request to be examined in a different position.[17]

One subtext here is that those who would benefit from cervical screening, are more likely to have a passive or deferential role defined for them in medical encounters, even when a more consensual and person-centred screening ought to be available. The Eve Appeal is making a relatively simple – but valuable and important – epistemic intervention, supplying, and disseminating information that is difficult to find and access elsewhere and likely to be opaque even during screenings. As the Appeal observes, 'knowledge is power'.[18] For some, this might be the end of the story. Newly confident that they can work with their nurse or doctor to author a less painful or difficult experience, they might book a screening where before they would have deferred, and use the tools provided by the campaign to effectively argue for what they need. The stakes involved in this knowledge being received and understood are high; freely accessible and widely publicized information on symptoms, risks, testing, and self-advocacy in health systems are important epistemic determinants of health.

However, this attempt at imparting knowledge gestures at broader and more complicated epistemic problems. The Eve Appeal suggests 'asking for information on cervical screening in Easy Read or in your preferred language', pulling focus to the need to provide knowledge in an appropriate format for people with learning disabilities and second language speakers.[19] There are Easy Read resources on cervical screening on the UK National Health Service (NHS) and Macmillan Cancer Support websites, but it is unclear whether these are proactively provided or simply available to be found, an important epistemic distinction. Of the advice offered by the Appeal, the NHS Easy Read guide includes the right to halt the screening ('you can stop the test at any time'), but relays nothing about the size of the speculum or the length of appointment, and specifies a default position for examination ('the nurse or doctor will ask you to lie on a bed with your knees bent').[20] The Macmillan Easy Read guide makes similar omissions, and doesn't communicate the ability to stop.[21] This is a clear example of a vulnerablised group prevented from accessing knowledge they deserve, with potentially detrimental consequences for health and for avoidable or reducible anxiety, pain, and discomfort.

The Eve Appeal has also created a comprehensive guide for trans, non-binary, and intersex people. This spotlights two further ways that health and just access to healthcare can be epistemically determined. As the Appeal puts it, ‘there isn’t much information out there if you are trans, non-binary, or intersex’.[22] Work on epistemic injustice has repeatedly demonstrated how this kind of knowledge is pushed to the margins, further disadvantaging people who are already likely to have a vexed and difficult – if not openly traumatizing – relationship with health systems.[23] The Appeal acknowledges this, including the following advice under the heading ‘if you have a bad experience’: ‘you may encounter health care professionals who lack knowledge of trans, non-binary, and intersex identities. This can make discussing your needs more difficult or result in a bad experience’.[24]

In this instance, it is healthcare professionals who lack, wilfully ignore, or disavow the necessary knowledge to provide fair and effective care. This is also a relatively rare moment where the Appeal recognizes that its core message of ‘discussing your needs’ has the potential to be fraught. Cis women have a long history of being dismissed or condescended to, and putting the knowledge provided by the Appeal into practice is easier said than done even for the most privileged, let alone when intersecting factors such as race, class, or health status are taken into account.[25] Even amidst important moves to transform healthcare into a partnership between professionals and ill persons, medical interactions involve norms that are often epistemically constraining.

Finally, complex negotiations such as these take place within broader epistemic processes of negation and resistance. These processes bear on how knowledge about health, illness, minds and bodies is politically situated and shaped. Work in disability studies emphasises that the ‘insider knowledges [of people with learning disabilities] are excluded from society’s historical and cultural imaginary’.[26] This also applies to medical imaginaries, with screening tests and the information which accompanies them unlikely to have been co-designed by people with learning disabilities, even when it has them in mind. Other forms of knowledge can also be deliberately erased, as part of political programmes of delegitimization. Amidst a government purge of ‘woke’ terminologies in the US, significant attempts have been made to drive information on trans health underground, and to replace it with deliberate misinformation.[27] In this wilfully ignorant framing, the only people who need cervical screenings are ‘women’, defined in particular and exclusionary ways, and knowledge outside of these parameters is ignored.

In what follows, we offer concepts and case studies which explicate the epistemic determinants of health and draw them into an interconnected and mutually responsive framework. The report begins with five key concepts: epistemic agency, phenomenology, intelligibility, affective injustice, and testimonial smothering, before discussing six case studies: silence and bipolar disorder, psychotic symptoms in young people, psycho-oncology, dementia, vaccine hesitancy and its determinants, reproductive epistemic injustice, and loneliness and the history of knowledge. It then spotlights a co-produced research project, the Agency-in-practice team, and their insights on young people’s mental health services; provides a number of practical suggestions, further reading and resources; and summarises the work of EPIC members behind the report. The primary aim of this document is to develop a new interpretive framework for understanding the epistemic determinants of health, paying particular attention to how epistemic injustices in healthcare are influenced by social, cultural, legal, and economic determinants rooted in the unequal distribution of power, credibility, and resources. We hope this will set in motion a collective project of work, with researchers and policymakers taking up the premise we have begun (and will continue) to articulate, evidence, and define.

2. Concepts

2.1. Epistemic agency

In successful social interactions we recognise each other's epistemic agency. What does this mean? We recognise that the person we are interacting with has a valuable perspective to share and valid concerns to express, and so there can be a useful exchange of information between us.[28] Moreover, we recognise that they have a variety of goals and interests and that they can contribute to change and participate in decision-making and problem-solving. Even if we end up disagreeing with their perspective on themselves or the world, their proposed course of action, or the solutions they offer to common problems, we deem them worthy of engagement and accept them as partners in our shared epistemic projects.[29]

There are social interactions in which a person's epistemic agency is undermined due to aspects of that person's identity (e.g. age, gender, race, socio-economic status, health, etc.) that trigger negative stereotypes. As a result, that person's perspective may be dismissed without prior engagement, their concerns may be thought to be illegitimate before they are even explored, and the complexity of their goals and interests may not be acknowledged. In such cases, the person is likely to be excluded from shared epistemic projects, that is, projects that involve knowledge exchange, collective decision-making or problem-solving, because they are not thought to be sufficiently competent to make a genuine contribution.

Due to the societal stigma associated with poor mental health, a person's epistemic agency is often questioned when they receive a psychiatric diagnosis. This affects many of their social interactions; with family, friends, in school, at work, and in the clinic. The capacity to make a valuable contribution to exchanges of information in someone diagnosed with highly stigmatised conditions, such as schizophrenia or dementia, is routinely challenged. Often this results in the person being silenced or dismissed altogether: their views are neither solicited nor valued.[30]

In some circumstances, epistemic agency is undermined in more subtle ways. In cases of harmful inclusion and extracted testimony, the perspective of the person may be actively sought but accepted and integrated in a body of shared knowledge only when it matches the interpretive framework of another person who is believed to be more authoritative. For instance, a person with thoughts of suicide may describe themselves as 'miserable', and a healthcare practitioner may challenge that description based on the person's facial expression. The person may superficially agree with the practitioner's interpretation of the situation to stop being challenged.[31]

In cases of contributory injustice, the very nature of a person's contribution to the exchange is distorted, leading to discounting that contribution. For instance, the behaviour of a person with

Alzheimer's disease may be described by a carer as 'challenging', and may be presented as a symptom of dementia, when it is an expression of the person's discomfort at having their preferences ignored or their privacy invaded. This often happens because the person with dementia is no longer thought of as an agent with individual preferences who can shape their lives according to their goals and interests.[32]

A mental health crisis is already a situation where a person's sense of agency is compromised: people tend to feel helpless and lacking control when they are overwhelmed by negative emotions.[33] The stigma associated with mental illness may cause further challenges to a person's sense of agency as a result of disempowering interactions, even interactions with the people who should be able to provide support, such as healthcare professionals.

EPISTEMIC JUSTICE IN HEALTHCARE

PATIENTS AS AGENTS, PERSONS, AND COLLABORATORS

AGENTS HAVE A PERSPECTIVE ON THE WORLD.	AGENTS HAVE MULTIPLE NEEDS AND INTERESTS.	AGENTS ACT TO FULFILL THEIR GOALS.	AGENTS COLLABORATE ON SHARED PROJECTS.
Healthcare professionals engage with patients' perspectives and legitimise their concerns.	Healthcare professionals treat patients as persons, not just as an object to label or a problem to solve.	Healthcare professionals acknowledge that patients can contribute to positive change.	Healthcare professionals involve patients in shared problem solving and decision making.

Fig. I: Table on the role of patients in clinical interactions.[34]

2.2. Phenomenology

Phenomenology is a method in philosophy that centres its study on human experience. A phenomenological study of ill health illuminates the experience, shedding light on its varied and complex nature, and is both a mode of theoretical study and a lived scrutiny of one's experiences. It is relevant to epistemic injustice because it enables the development of rich, nuanced analyses of experiences of illness, revealing their shared features while retaining an awareness of their idiosyncrasies. The approach utilises central phenomenological concepts, such as Martin Heidegger's 'being in the world,' and Maurice Merleau-Ponty's 'body-subject,' to offer a robust account of the significance of illness and how it affects human life in profound and multiple ways.[35] This approach secures such analyses against reductive medical jargon and rigid social scripts, which threaten to reduce a varied and diverse experience to narrow socially sanctioned narratives (for example that ill persons are heroes, or that illness is a journey).

A phenomenological analysis of illness can also be used to explore how meaning and intelligibility depend on consistent patterns of embodiment.[36] When these patterns are disrupted, meaning is affected and one's sense of belonging or being at home in the world can be severed. However, such phenomenological exploration is grounded in particular experiences that beset ill people. These experiences are not to be mined and then discarded in favor of a philosophical generalisation. They remain at the heart of the phenomenological analysis and the movement from subjective, idiosyncratic experience to more general philosophical analysis and back is intrinsic to this method. As such, this method is useful for understanding ill persons' experiences and viewpoints, and their significance in interactions with health professionals.

Phenomenology has historically strong ties with medical care and research, as exemplified in the phenomenological psychopathology movement which arose in the second half of the 20th-century.[37] A key insight of the movement is that people's lived experience of ill-health - what it means to live with illness - is often underappreciated in healthcare settings and biomedical research. Such dismissal of life experiences can increase the risk of epistemic injustice, particularly when ill health intersects with other categories such as race and gender, or exacerbated by poverty or other adverse life events.[38] This applies to both somatic and mental disorder (although the distinction itself is problematic).[39] This is because lived experience is often characterised as 'subjective' and unreliable compared to other, supposedly more 'objective,' forms of measurement.[40]

Biomedicine tends to operate by examining behaviour or external signs of illness in order to determine the presence of pathology. However, this can be ineffectual and may lead to harm when interpretations of a person's behaviour don't match how they experience their situation (although this differs greatly between types of disorder).[41] Key information needed to determine the nature of the pathology or the appropriate course of treatment should include the ill person's own understanding of their condition, as well as their goals and values. This can be particularly significant in mental ill-health, where diagnoses are mostly based on changes in experiences and behaviour relative to norms, rather than physiological markers, and many interventions rely on detailed understanding of these experiences.

The assumption that ill persons' reports of their experience are less medically relevant than objective markers such as blood tests increases the likelihood of epistemic injustice in healthcare because valuable information necessary for good care might be missed. It may also prevent full understanding of illness and distress insofar as the descriptions of disorder categories, such as mental disorder diagnoses or medically contested conditions, fail to reflect their experiences. Clinicians may also believe that being an unreliable knower in one aspect (such as experiencing delusions) impacts more broadly on their other experience and knowledge claims, hence creating a risk that the ill person is seen as unreliable or inaccurate more generally.[42]

Epistemic injustice may also arise in communications between health professionals and ill persons, or in decision-making processes that exclude ill persons, often resulting in unproductive conversations where the ill person and clinician talk past each other, even when lived experience is the heart of that conversation.[43] Time pressure, stress, and institutional demands often make interactions more pressurised, leading to poorer decision making. In such instances, a phenomenological perspective can help overcome communicative barriers by revealing fundamental aspects of illness experience that can be shared by both ill person and clinician, even when the content of the experiences differs.[44] Such shared aspects of illness include the loss of wholeness, loss of autonomy, loss of control and loss of the familiar world.[45] Most importantly, at the root of these shared experiences is the body, which is fundamental to all our experiences, perceptions, and action. As the phenomenologist Maurice Merleau-Ponty emphasised, the body is the starting point for perception; we may be embodied in different ways, but perception and action arise from and are rooted in the body.[46] This is critical for understanding ill health because it is experienced first and foremost as an embodied phenomenon. Hence, our ways of thinking, describing, understanding and sharing illness experiences must be rooted in an embodied worldview.

Merleau-Ponty also characterised language as continuous with action; language is a gesture towards the world, akin to pointing one's finger or waving one's hand, and, just like the gesture, language is embodied. Our voices, for example, may just be another way of pointing to the world. Knowing this, the phenomenological approach suggests that in order to communicate effectively with ill persons so as to better understand their lived experience, we shouldn't seek to map our language and experiences onto theirs. Instead, we should look more closely at what their language and gestures are pointing towards in the world. Ill persons will intentionally and unintentionally say what is meaningful to them, describing their experience or even sitting in silence; healthcare professionals can and should actively attend to the meaning that ill person is expressing.[47]

Phenomenology reveals how cases of miscommunication in healthcare may occur. Such cases can arise when illness fundamentally changes what the ill person finds to be meaningful, as well as their priorities and the context in which their illness is lived.[48] In this way, phenomenology - as a method that brings experience into the foreground - can help improve healthcare. With a phenomenological approach, we can better incorporate what is meaningful to ill persons into research and treatment decisions. This can help reduce the risk of epistemic inequalities between ill persons, healthcare professionals, and researchers.

Resisting the impulse to categorize, define, and reduce experience is a major task of phenomenology. In the case of illness, phenomenology can serve as an antidote for some kinds of hermeneutical injustice.[49] This kind of epistemic injustice is caused by epistemic marginalization in which the dominant interpretation, in this case the biomedical view, is accepted as accurate, true, and fully representative of the reality of illness. Hermeneutical injustice arises from a lack in interpretative resources that would enable an alternative understanding of the experience of illness. As long as patients rely heavily on medical jargon and manners of speaking about their illness as interpretive resources, an alternative interpretation cannot easily emerge. But if ill persons insist on developing their own interpretations and resisting pre-determined ones (e.g., resisting the biomedical view of one's illness as reducible to disease), it can be experienced and articulated idiosyncratically, subjectively, and non-reductively.

The phenomenological patient toolkit provides ill persons with tools for cultivating alternative, non-dominant interpretations of their illness experience.[50] It is also designed to help patients move away from the natural attitude towards illness. The toolkit provides a nonjudgmental, supportive, and open context which can help ill persons make their own sense of their experience of illness, using phenomenology. Bracketing the natural attitude toward illness suspends the belief in the reality of an objective disease entity. This suspension does not deny the objective reality of disease processes, but shifting the focus away from the disease entity and toward one's own experience of it can disclose new features of this experience, as well as giving ownership over the illness experience and the ensuing process of sense-making.

Phenomenologically attuned engagement with others is a key moral and practical method for ensuring connection, care, respect, and person-centered care. This is so especially when we consider the care we extend to those who are ill, suffering, in need, or in crisis, and those who are unable to care for themselves (the very young and the very old, for example). The attentiveness, focus on perception, openness to different lifeforms and ways of being, and the varied concepts phenomenology offers us, are all powerful tools to articulate and understand what makes good health care. For these reasons, and in these ways, phenomenology is a prime ethical and practical tool for promoting health justice and epistemic justice. Phenomenological methods and principles ought to be utilised routinely in medical and health care education, training, and practice. There are structural, political, and other factors that determine healthcare quality but the prioritisation of the experiencing person and of first-person accounts make phenomenology a deeply ethical stance that ought to ground good person-centered health care.

2.3. Pathophobia

Chronically ill persons can be subjected to harmful attitudes and behaviours, including, neglect, discrimination, and exploitation. While these patterns of mistreatment are often related to racism, sexism, and other recognised kinds of oppression, they are in this case distinctive to illness. The distinctive mistreatment of ill persons is called *pathophobia*.[51]

Introduced by Kidd in 2018 and elaborated in 2021 and 2025 by Kidd and Carel, pathophobia is modelled after other concepts used to analyse forms of oppression, such as sexism and Islamophobia.[52] It is intended as a companion to sanism (discrimination against persons with mental health problems) and ableism (discrimination against persons with disabilities). Pathophobia expresses itself in attitudes towards ill people, ways of thinking and talking about illness, and kinds of harmful behaviour. Many illness narratives offer descriptions of pathophobic attitudes and actions, perpetrated by individuals, groups, or institutions. For example, in their recent book *Being Ill: On Sickness, Care, and Abandonment*, Neil Vickers and Derek Bolton explore the endocrinologist David Rabin's important account of interpersonal and professional isolation following his diagnosis with amyotrophic lateral sclerosis (ALS) in 1978.[53] Colleagues and friends – in some instances quite literally – turned away, in what he and his wife Pauline termed 'the pariah syndrome'.[54]

Societies can also be described as pathophobic, if their dominant ways of understanding illness and treating ill people are negative. So, just as there are racist individuals, sexist groups, or homophobic societies, there are pathophobic individuals, groups, and societies. Kidd structures pathophobia in terms of five broad categories of harms and wrongs. These are: *aversion*, *banality*, *callousness*, *insensitivity*, and *untruthfulness*. Some ill persons experience all five kinds, others only experience some of them. These types of pathophobia can take different forms, depending on the social status, relationships, and cultural contexts of the ill person in question.[55]

Aversive pathophobia are failures to engage with chronically ill persons in proper and respectful ways. Some examples include rudeness and condescension, and hostile interpersonal behaviour, such as intrusive staring. Such actions signal negative attitudes towards the ill person, and which cause distress and block the possibility of respectful interaction. Pathophobic aversion is often driven by alarm and disgust at the appearance and behaviour of ill people, so is more likely to affect those with 'visible illnesses' (for example, hair loss caused by cancer treatments). Aversive behaviour, if it becomes constant, also feeds a sense of social isolation and disconnection with other people, and erodes trust.[56]

Pathophobic banality are failures to properly understand the complexities and particularities of experiences of illness. Ill people often report that other people do not ‘get’ what it is like to be ill, or that people rely on facile, distorted ideas about the life and struggles of ill people. Banality is often a feature of the ways that people think and talk about illness – in the form of clichés, trite reassurances, and bland descriptions of what are, in fact, complicated experiences. Of course, many experiences of illness are extremely difficult to understand and describe; however, pathophobic banality makes that difficult task far harder.[57]

Pathophobic callousness are failures of empathetic care and concern for ill persons. While all human beings require care, empathy, and support, ill persons often have specific needs, due to the effects of their illness and its treatment or management. There are two broad kinds of pathophobic callousness. One is *pathophobic abandonment*, failures to provide care and support, including negligence, carelessness, and a selfish privileging of one’s own preferences over the needs of ill persons. this can be a feature of healthcare practitioners, but also of friends, family members, and strangers. Another is *pathophobic abuse*, the deliberate exploitation of the needs and vulnerabilities of ill persons. This includes physical, psychological, economic, and sexual abuse, cruelty, mean-spiritedness and spitefulness, and the withholding of medical support or emotional care. When tracing back, we can see that initial acts of abandonment can sometimes develop into more severe abuse.[58]

Pathophobic insensitivity are failures to appreciate the intimate, personal, and distressing nature of illness. Being ill often has severe effects on the most sensitive dimensions of a person’s life, such as their financial status, mental health, sexual appetites and abilities, and so on. If these sensitivities are not respected, one can cause severe distress and cause the ill person serious social barriers, such as shame and embarrassment. Pathophobic insensitivity can include ‘morbid curiosity’ about the ill person’s illness, or tactless ways of describing and speaking about illness (for instance, referring to a diagnosis of terminal illness as a ‘death sentence’). These are failures of sensitivity, respect, consideration, and tactfulness.[59]

Pathophobic untruthfulness are failures to seek and cultivate a properly truthful understanding of the realities of living with an illness. Many ill persons complain that people will not speak honestly of illness. Many accounts of illness tend to be one-sidedly optimistic, glossing over the emotionally raw realities of suffering, and ignoring or downplaying the struggles, anxieties, and disappointments that are often entailed by illness. In some cases, less-than-truthful accounts of illness can be helpful, if they provide someone with the space to process their experiences. However, if our ways of thinking about illness become systematically untruthful, then we deny ourselves a properly accurate and complex appreciation of these extremely hard kinds of human experience.[60]

These five varieties of pathophobia manifest in attitudes, behaviours, ways of thinking and speaking about illness, and our wider conceptions of illness. They can be performed by individuals, social groups, or institutions. We can also think about policies and social structures as pathophobic. The concept of pathophobia is valuable in relation to health for two reasons. The first is that much of the reality, difficulty, and suffering of illness is due to pathophobia - which causes, worsens, and prolongs physical, psychological, and emotional distress. The second is that pathophobia is a feature of the social world. As such it intersects with sexism and racism, and is at the root of social and epistemic injustices, inequalities in healthcare and welfare support, and other problematic features of human societies. Each of Kidd’s five clusters positions ill people in epistemically constrained, devalued, or objectified ways. They form a critically important context for understanding why and how illness is so frequently accompanied by heightened epistemic struggle, even before the intersectional features of other forms of discrimination and prejudice are taken into account.

2.4. Intelligibility in psychiatry

When people with conditions such as psychosis, schizophrenia, or extreme depression report delusional beliefs to us, this can be some of the most baffling and least intelligible things we hear. How could someone possibly believe there is an entire city inside their body, or that someone else is putting thoughts into their head, or that they are dead? It's natural to think that if someone reports beliefs of this kind, they can't know much about their own state and that of the external world.

The irrationality of these beliefs has given rise to theorising that they are 'empty speech acts', merely outputs of a broken cognitive system with no intelligible meaning.[61] Some delusions, particularly those involved in schizophrenia, have been described as 'un-understandable' and without cause.[62] This reductive stance has been contested, however, in the argument that 'madness' can be comprehensible and that proper engagement with delusional speech is an appropriate source of therapeutic insight.[63] More recently, concepts such as 'madness-as-strategy' signal a decisive move away from conceptualising psychopathology primarily as a deficit in functioning.[64] Rather, psychopathology can be seen as cognitive systems functioning *as designed*, in order to help the individual cope, receive help, and *maintain* functioning.

Taking a more comprehensive and holistic look at wider life contexts can illuminate these aspects of delusional beliefs. Comprehensive interviews, for instance, suggest that delusional beliefs could play a protective role within difficult circumstances.[65] Delusions may not only be meaningful, but *give* meaning, by enhancing a person's sense of agency and having a meaningful life.[66]

Making sense of, and creating meaning from, our experiences is a shared endeavour with those around us. We often discuss our feelings and experiences with friends and others in order to both express and better understand them. Those who experience delusions and hallucinations are more likely to find themselves interacting with healthcare professionals. It is an injustice for them not to receive the same kind of authentic engagement and recognition of their sense-making capacities on account of their beliefs being unusual. This is because their beliefs being unusual isn't 'random' or for no reason. Rather, those with delusions are dealing with extremely strong and unsettling changes in their feelings, perceptions, or general mood.[67] This means that their beliefs are unusual, but it doesn't mean that no sort of meaningful interaction can be had.

To provide good care, health professionals should recognise the wider context and narratives of people's lives, and consider sources of trauma and intense anomalous feelings which are new, difficult and transformative for them.[68] It may be that the beliefs shared by those with delusions have *metaphorical* meaning, and although they hold those beliefs to be literally true, they can be grasped and interpreted metaphorically.[69] The more that peers and healthcare professionals engage with the context of delusional beliefs and the overall circumstances of the ill person behind them, the more we see that there is plenty that people with delusions know and understand about themselves and the world.

Miranda Fricker suggests that specific virtues of good listening may help prevent injustices against those with mental health conditions.[70] Assuming that someone is incapable of discerning meaning from their circumstances because they have some form of psychopathology is one of these injustices, as it is a prejudiced assumption. Fricker advises mindfulness of identity prejudices and stigmas associated with marginalised groups when listening to their testimony, to avoid unfair dismissal. More recent work emphasises curiosity as one such virtue which will aid in treating people justly, and uncovering the meaning and intelligibility of their claims.[71] Curiosity can drive the listener to seek out and consider all of the relevant contextual information of a person's life, recognise their valuable perspective, and avoid unjustly withholding shared meaning-making practices from that person, when this is something we all require for meaningful lives.

2.5. Affective injustice

Certain emotions, such as anger, can be understood as social acts. We express anger to try to communicate something, to draw someone's attention to something that we think is wrong.[72] If we understand anger as an attempt to communicate knowledge to others - as a social act involving claims to knowledge - we can see that how people receive others' emotions can cause and compound epistemic injustice in healthcare settings.

Some epistemic injustices are not (only) about being unfairly dismissed or silenced regarding straightforward knowledge claims, but about unfairly losing the ability to influence others with one's emotional expression. This is referred to as affective injustice. The impact of having one's emotional expressions dismissed or otherwise badly received due to prejudice can be significant: for example, studies suggest that anger expression increases influence for men, but decreases influence for women.[73] Consequently, being alert to how the prejudiced marginalisation of emotional expression unfairly shapes the perceived credibility of ill persons is crucial. For example, prejudice against ill people may cause an ill person's emotional assessments of situations to be automatically perceived as disproportionate or inappropriate. When this happens, the ill person is not seen as a person who can draw attention to injustice and hardship, but rather as someone lacking emotion regulation skills and resilience.[74] If emotional responses to situations are consistently patronised, pathologized, or undermined over time, this may obstruct the ill person's long-term ability to make sense of their emotional lives. This, in turn, can undermine people's emotion regulation skills.

Norms about what types of emotional expression are appropriate are built into current practices in healthcare, yet these norms require attention. For instance, built into borderline personality disorder (BPD) is a diagnostic criterion of 'inappropriate anger'. However, there is no guidance on how to distinguish between appropriate and inappropriate anger. This is particularly problematic given the stigmatisation of women's anger.[75] The anger of women with BPD is more likely to be interpreted as a pathological 'outburst' than a reasonable response to unjust or difficult circumstances. This ambiguity, coupled with sexist implicit biases, can result in the anger of women with BPD being seen as inappropriate only because of prejudice. If an ill person anticipates that their emotional expressions will be dismissed by healthcare professionals as a sign of pathology, they may choose to protect themselves by socially isolating and disengaging with services.[76]

This is not to suggest that all emotional expressions should be validated as appropriate and proportionate. Rather, what is important is to develop greater awareness of the role of prejudice in unfairly downgrading the significance and reasons for ill persons' emotional expressions. Emotional dysregulation can be an expected response to illness, but emotional dysregulation does not imply that the ill person does not have anything important to communicate.[77] Continued attention to how emotional expression is received in clinical encounters is crucial to improving health care. Healthcare professionals might find it productive to consider how ill persons may be wronged as persons whose emotional expressions have a communicative function.

2.6. Testimonial smothering

Testimonial smothering - understood as a form of silencing - occurs when a person withholds knowledge about something because they reasonably believe that their testimony will be refused or misunderstood in a way that causes them harm. This may involve leaving out details or altering how information is presented in order to make it more intelligible to others.[78] The concept has recently been used to explain low rates of domestic violence disclosure in healthcare settings.[79]

Unlike everyday attempts to communicate effectively which aim to share necessary and pertinent information, testimonial smothering involves the self-censoring of information that is important and relevant to the exchange. Due to an awareness of the influence of prejudice, negative stereotyping, or a feeling of shame, the speaker decides what information to share based on how receptive they believe their audience will be and how information may be misinterpreted or misunderstood. This concept is apt for considering how prejudice and stigma against ill people can erode trust, disincentivise honesty, and encourage self-censorship.[80]

Sometimes in interactions with healthcare professionals, ill persons' attempts to communicate will fail or lead to unintended consequences. This may be due, among other factors, to an unwillingness or inability of healthcare professionals to interpret or understand the ill person as they intended; harmful stereotypes; or ill-suited diagnostic frameworks. In many cases, such misunderstandings or misinterpretations will be unintentional, or simply due to fixable gaps in knowledge.[81] But in other cases, they can be more insidious. Testimonial smothering can adversely affect medical care and health outcomes in a range of contexts; research has shown it to be especially salient in stigmatised conditions across somatic medicine and psychiatry.[82] It is a particular risk when it comes to conditions for which there are no firm biomarkers. In such cases, verbal communication and descriptions of subjective experience are vital for informing the clinical protocol [see concept 2.2].

Ill persons can be wary of providing information that may trigger implicit biases or prejudices in healthcare professionals, thus adversely affecting their care. For example, disclosing a previous psychiatric diagnosis may increase the risk that healthcare professionals will dismiss new symptoms as having psychogenic rather than somatic causes. These dynamics are common where the illness in question is contested or prone to being over-psychologised. For example, ill persons experiencing chronic pain may face stigma or prejudice when seeking treatment. Experiencing stigma from healthcare professionals may lead ill persons to make conscious and careful choices about how they describe their pain or which details of their medical history they include.[83]

Due to a history of pervasive stigma, testimonial smothering is also common in functional neurological disorders such as chronic fatigue syndrome/myalgic encephalomyelitis, fibromyalgia, and irritable bowel syndrome, as well as functional seizures, tremors and tics.

These conditions are not well understood, yet they are highly prevalent and place a significant strain on healthcare systems.[84] Clinical guidance on how to manage and treat ill persons with such conditions is frequently unclear. This means that there is room for personal prejudice from the healthcare professional to influence the ill person's care plan. Ambiguous guidance, combined with the stigmatisation of mental illness, increases the risk of healthcare professionals assuming that the ill person's complaint is feigned or entirely psychological in nature.[85]

Ill persons are very often aware of this, and testimonial smothering is a protective strategy that has been developed in response. Withholding information is not inherently bad: in fact sometimes it can be a good thing [see case study 3.1].[86] However, it is important to recognise the pernicious forces behind tactical silences. We need resources with which to better understand conditions like chronic pain and chronic fatigue, and these resources are best developed through open, curious and trustful collaboration between ill persons and medical professionals.

3. EPIC Case studies

3.1. Silence in bipolar disorder

Silence in the context of mental illness is often perceived as something negative – as though it is imposed on individuals by others and must be broken. In many cases, it is and should be. Epistemic injustice, social stigma, ignorance, and insensitivity are some of the factors that can lead individuals to avoid talking about their mental illness or even avoid conversations altogether.[87] This can have serious epistemic and medical consequences, suppressing information that might otherwise enable people to receive the support they need and help improve our collective medical understanding of mental illness (see entry on testimonial smothering).

However, equating all silence in mental illness with socially imposed harms, such as testimonial and hermeneutical injustice, also carries serious risks. In particular, it may lead people to overlook or misinterpret other kinds of silence associated with mental illness to the detriment of those who suffer from it. First-person experiences with bipolar disorder demonstrate the diversity of silence in mental illness and the dangers of ignoring that diversity. Bipolar disorder often involves alternating episodes of depression and mania. During these episodes, an individual’s relationship to silence can change radically.

While depressed, individuals with bipolar disorder may feel unable to think or speak.[88] Andrew Solomon, an author with bipolar disorder, recalls that during one severe episode of depression, he ‘could not manage to say much’. Elaborating, he writes: ‘Words, with which I have always been intimate, seemed suddenly very elaborate, difficult metaphors the use of which entailed much more energy than I could possibly muster'.[89] Understandably, experiences such as this can be intensely distressing and disempowering. Since they cannot reliably communicate, individuals may feel lonely and isolated even around people who care about them.[90]

By contrast, during mania, a person may feel unable to be silent or that being silent suddenly requires extreme effort. For example, another author with bipolar disorder, Teri Cheney, describes the following experience while attending a party during a manic episode:

> I actually stopped talking. I actually listened. So I knew that I wasn't all the way manic… I was maybe three-quarters of the way up… where the urges are sometimes negotiable and swivel chairs can still make a difference. At three-quarters up, my mind is running fast, but not so fast that I can't, with an intense effort, shut up and listen.[91]

The inability to be silent can also be intensely distressing and disempowering. One reason for this is that, just like speech, silence is an essential aspect of our epistemic agency. Silence can be a way of communicating knowledge when words fall short, of withholding knowledge that others cannot be trusted with, and of gaining knowledge through listening. As Cheney's account suggests, in mania, the ability to use silence in these ways can be significantly disrupted. Recovery or effective management of the illness often involves regaining the ability to exercise this silent agency.[92]

For a person with bipolar disorder, silence can signify illness or health, disempowerment or empowerment. Yet, neither extreme fits the assumption that silence is always a socially imposed harm that we should try to break by urging people to speak, sometimes regardless of context.[93] In fact, narrow assumptions about the nature of silence in mental illness can worsen vulnerabilities and engender epistemic injustices as well as other harms by prejudicing how others interpret and respond to the silences of people with mental illness. Potential consequences include unwarranted interpretations of their silence, paternalistic attempts to speak for them, and misguided efforts to break silences that the individual cannot – or has good reasons not to – break.

My case study explores these and other dimensions of silence in bipolar through first-person accounts of this experience of this illness, drawn from interviews and autobiographies. While the research is still ongoing, three things are clear from the work that we have completed so far:

1. Silence in mental illness is a diverse phenomenon and is often a vital means for people with mental illness to navigate the epistemic predicaments they face.
2. Governments, healthcare institutions, charities, and NGOs need to find ways to combat stigma and encourage people to seek support for their mental distress without marginalizing or pathologizing those who are silent.
3. More research is required on different kinds of silence in different illnesses and in different cultures – since cultural meanings of silence can vary tremendously – to better understand their roles and meanings, and to determine how best to support ill persons who are silent.[94]

3.2. Loneliness and the history of knowledge

Following calls from contributors to this report (Kidd and Carel) to ‘go “all the way down” into the deep socio-epistemic structures of our biomedical and healthcare systems, and “all the way back” through the contingent histories that shaped them’, work at the intersections of history and philosophy can build critical genealogies of epistemic challenges in the present day.[95] This call goes beyond an opportunity to excavate and understand past instances of epistemic injustice, although this is illuminating. Rather, its goal is to reveal how and why different systems of knowledge, evidence, and practice were built to be – and resist attempts to render them less – epistemically unjust. In this sense, epistemic injustice is less a stable referent which can be applied usefully to any time and place, than a way of naming a set of concerns which have only been possible under distinct historical conditions.

For example, ill people in the more distant past have certainly been ignored, dismissed, silenced, shamed, and condescended to, in ways that are – or were – epistemically unjust. But without a countervailing set of meanings, which assert that their knowledge is epistemically valuable and not just information to be extracted, such exchanges are not typically catalysed – or even necessarily experienced – as injustices. The primary tensions today, read historically, might best be understood as taking place in and over the fault lines between a set of investments in epistemic justice, of which the current report is an example, and systems built and elaborated before a widespread valuation of ‘lived experience’ was built in relation to health and illness. Historical work has shown how different liberational movements entered into critical struggles over knowledge, meaning, medicine, and care, particularly after the late 1960s. For disability and patient’s rights activists, or the psychiatric survivor movement, these were central to the affirmation of their insider knowledge as an alternative source of epistemic power. Other activists, for example, on race, gender, and sexuality, also took sight at the medical dimensions of their oppression and the ways that their marginalisation framed unjust health experiences and access to effective treatment.[96] Their insights – and the broader emphasis on experience and voice in health systems promoted by anti-paternalist theories of general practice, or in patient-centred medicine – can be understood as subject to (ongoing) institutional resistance.

To take a more specific example, this case study focuses on the history of loneliness. It explores the epistemic difficulties faced by lonely people that can be understood as resulting in part from the dominant interpretive resources usually drawn on to describe, explicate, and ameliorate loneliness. These difficulties make loneliness (more) difficult to speak about, and assemble unwanted (and frequently false) knowledge around the person experiencing it. Even if knowledge on loneliness in the present is created in epistemically just ways, it sits on a deep silt of knowledge on loneliness which was created in epistemically unjust ways, and which significantly delimits the possibilities for exchanges and processes which cede epistemic power to the lonely or elevate and centre thick, marginalised, experiential accounts. Loneliness studies took shape in part around attributions of narcissism and self-pity, and frequently positioned lonely people as ‘not-knowers’, people who were unable to understand and communicate their own emotions and experiences; an early investment in the existential dimensions of loneliness emphasised the role of self-alienation, with a concomitant positioning of lonely people as unreliable witnesses and experiencers.[97] Even when a field changes, this is an inheritance which is hard to shrug off, pulling in as it does a set of protocols (i.e., around the compensatory interpretive power of the psychiatrist, or the lonely patient as attention-seeker) which become embedded in therapies and institutions as well as the bedrock knowledge that they operate from.[98] The question then becomes how these genealogies work in the present to stifle movement toward epistemically just knowledge and practice, even (and particularly) when almost everyone engaged in the argument agrees – at least superficially – that such shifts are ethically, theoretically, and practically warranted.

Historical research into the epistemic objects that form and frame knowledge, too, can provide an important basis for thinking critically about what epistemically just loneliness research might resemble. Developments such as the creation, proliferation, and ubiquity of quantitative ratings (e.g. the UCLA and De Jong Gierveld loneliness scales) have rich histories with significant implications for how they work, and their use today frequently black-boxes important epistemic processes; whether on the part of their creators or of the raters themselves, who respond to questions which might seem basic or innocuous but in fact make intricate epistemic demands.[99] For example, the de Jong Gierveld scale item, 'I experience a general sense of emptiness', requires considerable interpretive and introspective labour; what does it mean to experience emptiness? What does it mean to not experience emptiness? Is that sense 'general', and how do you tell?[100] More complex still are the consequences produced by the reification of quantitative evidence, which pushes other forms of knowledge (such as experience, testimony, or analysis from humanities perspectives) to the margins. Rating scales can also have adverse effects on the people who use them and the ways they articulate and narrate their experiences, interjecting a rigid and impoverished conceptual framework over understandings more in tune with the raters' history and values.[101]

This case study takes a critical genealogical approach to a series of contingent historical contexts and processes which frame sites of epistemic contestation around loneliness in the present day. Interrogating problems such as measurement, medicalisation, and (de)politicisation, it shows how they structure and perpetuate different kinds of epistemic injustice. Research so far suggests several critical findings:

1. Epistemic determinants of health have distinct and observable histories, which can afford significant insights into how they work and how they can be acted on.
2. Epistemic problems around specific conditions or challenges are framed by their intellectual and practical genealogies; working towards epistemic justice might involve rethinking the sum of professional knowledge about them, and asking whether that knowledge works for the people it attempts to understand.
3. Research on loneliness can often be a source of epistemic containment and constraint, and researchers should consider how they can better facilitate the epistemic agency of the people they work with, and what knowledge and practice within loneliness studies needs to be contested or reimagined.

3.3. Vaccine hesitancy and its determinants

Vaccine hesitancy has been listed by the World Health Organization as one of the top ten global health threats of the 21st century. In response to the growing prevalence of the problem, WHO's Strategic Advisory Group of Experts on Immunization (SAGE) established a Working Group on Vaccine Hesitancy which, in 2014, issued a definition of the problem that has since been widely used and elaborated:

Vaccine hesitancy refers to delay in acceptance or refusal of vaccines despite availability of vaccination services. Vaccine hesitancy is complex and context-specific, varying across time, *place, and vaccines. It is influenced by factors such as complacency, convenience, and confidence.*

Crucial to this definition is a conceptualisation of the key factors behind vaccine hesitancy. Originally, these were: *complacency* (low general knowledge and awareness of high-risk diseases and the importance of vaccination), *convenience* (availability, accessibility, affordability of vaccination), and *confidence* (a lack of trust in vaccine safety and efficacy, systems, or policymakers). The 3C model spurred new research and was revised in 2018. Convenience was replaced by ‘constraint’, with important emphasis on structural *and* psychological barriers to vaccination, and two new factors were added: ‘calculation’ (engagement in gathering information) and ‘collective responsibility’ (willingness to protect others).

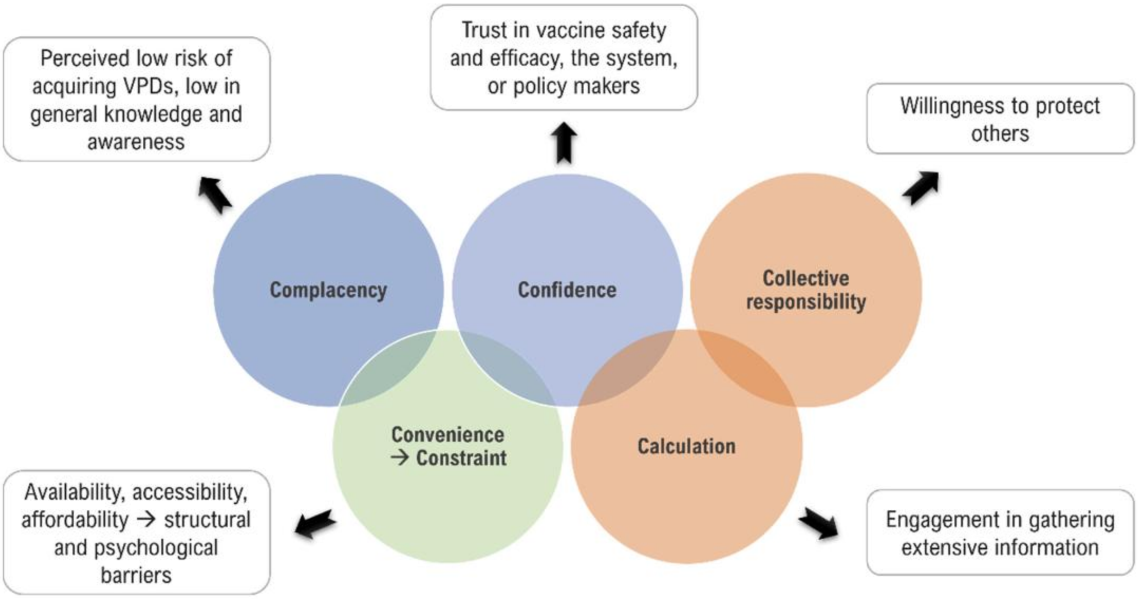

Fig. II: SAGE (Scientific Advisory Group for Emergencies, UK) vaccine hesitancy model.[102]

SAGE importantly delineated vaccine hesitancy as a new public health category that underscored knowledge as a crucial determinant. Yet, observers and critics have argued that how the 5C model frames vaccine hesitancy is problematic in at least two ways. First, it characterises the core determinant as a general lack of knowledge of vaccine safety and efficacy, of risks of vaccine-preventable diseases, of collective responsibility (the social value of herd immunity), and of how to access and use credible information and resources. Hesitancy is framed as the result of a *deficit* in basic medical, scientific and social knowledge of vaccines. Second, in framing vaccine hesitancy as a knowledge-deficit issue, the model supports an oversimplified solution in the form of more effective dissemination and communication of medical-scientific information.[103] This solution is oversimplified because it assumes that hesitancy is largely due to a lack of medico-scientific knowledge that can be redressed by the provision of such knowledge.

Despite recognising that vaccine hesitancy is both complex and context-dependant, framing it as a knowledge-deficit problem reflects a broader failure to take seriously experiences, meanings, and ways of understanding that people and communities bring to vaccines and the diseases they are meant to protect against.[104] Which is to say, the issue is not lack of knowledge but how knowledge people have and use determines their attitudes and behaviours towards vaccination. Knowledge-deficit frameworks have, often for reasons of expediency, skirted the complex epistemic, social and cultural roots of public mistrust of vaccines and the scientific institutions that promote them.[105] This has started to change. Increasingly, such frameworks have started to address historic mistrust of public health interventions as part of strategies to overcoming vaccine hesitancy.

However, there are other ways to tackle this issue. Rather than seek to remedy a perceived knowledge-deficit, the challenge is to give credence to, and understand, the knowledge people and communities possess about vaccination in order to get at the socio-historical and epistemic roots of hesitancy. While knowledge, attitudes and beliefs about vaccination have been extensively studied, this challenge has rarely been incorporated into vaccine policy-making.[106] For reasons that will be explored in this case study, vaccine policies have been marked by continual lack of engagement with – and often dismissal of – people's knowledge and experiences of vaccination, and by the absence of collectively generated and culturally specific resources that address, among other things, the efficacy, safety, and value of vaccines for different epistemic communities.

Epistemic injustice is a valuable new framework for understanding the determinants of vaccine hesitancy. Particularly relevant is work being done on epistemic injustice in global health.[107] Much of this work is anthropological but also grounded in historicising epistemic injustice in relation to colonial histories that have shaped health knowledge. Researchers have used the concept of the 'coloniality of knowledge' to highlight the colonial roots of global health and persistence of colonial ways of knowing in health policy and practices. This approach puts a spotlight on the processes by which certain ways of knowing – and knowers – are included and excluded in health policy-making and programmes. Such work asks how, why and with what consequences (Western) ways of knowing have been granted credibility and authority while non-Western ways of knowing health, illness and disease have not. These processes are key to how power works in healthcare systems. In turn, analysts have traced how global health policy has systematically excluded the voices, realities, ideas and experiences of marginalized groups it is designed to serve.[108] That is, it is girded by forms of *testimonial injustice* in which some knowers and ways of knowing are not deemed credible on the basis of their educational background, social or economic status, or identity. At the same time, global health problems and solutions have been typically framed in language and terminology that is inaccessible to most, and especially to marginalized groups. The result is the perpetuation of forms of *hermeneutical or interpretative injustice* in which people most in need are unable to contribute to, access or take-up knowledge that could prove vital to understanding, addressing and ameliorating their ill health. In certain instances, vaccine policy can produce what is called 'contributory injustice', where hermeneutical resources created by marginalized communities on vaccination are dismissed or discredited by policy-makers, because these communities are not seen as credible contributors to the epistemic task at hand.[109]

These issues are central to a case of the history of 'selective' vaccination policies for immigrant and ethnic minorities deemed at risk of tuberculosis in Britain. In 1994, the International Union Against Tuberculosis and Lung Disease set-out guidelines for countries to transition from universal to selective BCG vaccination.[110] Since the 1990s, the World Health Organisation has recommended ’selective’ vaccination for TB in countries with low incidence of the disease.[111] While formally adopted as general TB vaccination policy in Britain in 2005, selective vaccination had been implemented locally since the mid-1960s. The British case is thus valuable for tracking the long-term and changing development of this kind of vaccination policy.

Unlike universal or mass vaccination, which target entire age groups (i.e., infants or children) or populations, selective vaccination targets specific groups on the basis of identified clinical or epidemiological risks. Selective TB vaccination is an example of a vaccine policy based on risks associated with an individual’s ethnicity or national identity. In Britain, selective TB vaccination programmes have primarily concentrated on newborns and children with familial ties to the Indian sub-continent, sub-Sarahan Africa, and other countries with high rates of tuberculosis or who were born into immigrant communities in Britain with similar rates of infection. Selective vaccination has been framed by Britain’s changing ethnic, cultural, and epidemiological make-up, public health agendas, historic conceptions of tuberculosis as an immigrant problem and racialized risk, and the shifting economic rationalities of BCG vaccination.

Three major issues have emerged to date and are being explored as part of the research programme for this case study:

1. The study is examining the multiple challenges in developing and implementing selective TB programmes, including uncertainty about the efficacy of BCG vaccine in infants born into ethnic minority families, ill-defined selection criteria, and poor uptake.
2. The study is examining how immigrant and ethnic minorities’ knowledge and experiences of tuberculosis, BCG vaccination, and their relative risks, have been included or excluded from British tuberculosis vaccination policies and programmes.
3. The study is investigating how stigmatization or marginalization, resulting in forms of epistemic injustice, can be an unintended consequence of vaccine policy. In turn, the study examines or proposes approaches based on inclusive, effective cross-cultural communication and understanding to address epistemic determinants of vaccine hesitancy.

3.4. Psychotic symptoms in young people

Psychosis is a pertinent example of where epistemic injustice may arise due to its formal diagnostic description, as seen in the International Classification of Diseases’ (11) description of schizophrenia or other primary psychotic disorders as ‘impaired reality testing,’ and being linked to the presence of hallucinations and/or delusions. Such a description of psychosis may provide an in-principle reason for some to dismiss the experiences of people with psychosis as not pertaining to genuine knowledge about the world; people with psychosis have experiences that contradict what is commonly known about the world and how it operates, leading to the assumption that they are not adequate or reliable knowers in general.[112]

Psychosis is a disorder that most frequently manifests in younger populations, with the typical age of first episode of psychosis between late teens and early adulthood. Its onset can be linked to early developmental events and traumatic experiences, including poverty, bullying and abuse, racism, drug use, and migration. Some have suggested that children and young people may be particularly vulnerable to epistemic injustices and thus it is likely that people who experience psychosis are likely to have intersectional experiences of injustice resulting from their age and disorder.[113]

Baumtrog and Peach, for example, argue that children are often discredited or ignored, due to presuppositions that a) they engage in creative fantasy, roleplaying and lying, and therefore may not be trusted, even in cases where they face genuine harm, and b) that they simply know less and have inadequate experience compared to adults. Such attitudes are described as 'adultcentrism', the perspective that the adult experience should be the standard for knowledge.[114] Carel and Gyorffy (2014) claim that children and young people are particularly vulnerable to epistemic injustice arising from difficulty in distinguishing between characteristics that are genuine descriptors of a particular age group, and potentially harmful biases of adult health professionals towards children.[115] Given the significant developmental changes that occur during childhood , it is likely that children, adolescents and young adults may be considered less knowledgeable or reliable due to their age.

Empirical research confirms that young people with mental health difficulties experience epistemic injustice, and this is particularly the case for stigmatising conditions such as psychosis.[116] In recent work with young people who hear voices, objectification (where the person is reduced to their diagnosis) and infantilization (where the person is treated by default as if they did not have capacity) were found to be common experiences, especially in interactions with healthcare professionals.[117] Extreme cases, where people with acute psychosis cared for in the psychiatric ward experience coercion, present even higher risks of epistemic injustice, with potential loss of agency and dignity, sometimes leading to demoralisation and suicidal thoughts.[118]

The *intersectional* aspect to experiences of epistemic injustice has not yet been thoroughly investigated. Intersectionality is a term coined by Black feminist thinkers to describe how an individual can occupy multiple social groups which afford for different levels of credibility; being a white man, for example, may afford you more credibility than others in most circumstances, but being a white man who is also gay or working class may result in having one's testimony discredited in other situations.[119] This is a pertinent issue to consider as individuals from Black, Asian and Minority Ethnic (BAME) backgrounds are overrepresented in the population of young people with psychosis.[120] Many young people with psychosis experience additional prejudice against their testimony based on how they are racialised, for example, as well as their youth. Young people with psychosis are therefore likely to experience injustice arising from multiple features of their identities.

This issue becomes increasingly important to address when we consider the phenomena of 'intersectional invisibility'. People who sit at the intersection of various identities, such as individuals who are mixed race, are sometimes not seen to exemplify either identity (e.g. one is not perceived as either white or Black).[121] Because of this, individuals with complex identities may be marginalised epistemically within their own communities as they are not perceived to be 'full members' of those communities. Young people with psychosis can therefore face additional challenges in having their experiences recognised by peers, insofar as their experiences of psychosis mark them as 'atypical' members. This can result in young people feeling alienated and excluded from adopting or contributing knowledge to their own communities. Young people with psychosis are highly epistemically marginalised and isolated, with several detrimental impacts on their health and wellbeing.[122]

This case study examines the lived experience of young people with psychosis and how the epistemic injustices they face impact their sense of identity and belongingness. We also intend to find out from these interviews what young people think is important for a conversation around mental health to go well in order to make someone feel accepted. From this we hope to develop a toolkit and strategies for healthcare providers so they can avoid epistemic injustices in their interactions with young people. Research so far suggests three major points:

1. Epistemic injustices related to age are as yet only partially understood. Effective work with young people should factor in wider social and epistemic prejudices about their group, and understand them as implicated in the aetiology and treatment of psychosis.
2. Intersectionality is key to understanding how multiple identities or life histories can become subject to interlocking or nested epistemic injustices, reflecting (and perpetuating) the complexity of their marginalisation. These can be harder to identify, and require targeted training in clinical practice.
3. The development of a toolkit which aims at decreasing epistemic isolation with sensitivity to its intersectional composition has the potential for considerable ameliorative effects. Research to test this hypothesis – and efforts to scale it up into existing services – are productive avenues to pursue.

3.5. Psycho-oncology

Psycho-oncology is ‘the specialty aiming at studying the psychological, social and spiritual factors that affect the quality of life of cancer patients and their loved ones’.[123] A population affected by serious somatic and mental illness, including terminal illness, may be more vulnerable to epistemic injustice, arising from the combination of negative stereotypes about people who are ill, who have a mental illness, and who may not recover.[124]

In particular, medical interventions at the end of life are at risk of failing to provide dignity-oriented care, due to common prejudices about palliative care.[125] Palliation can be seen as futile when the main goal of care in general is perceived to be healing or curing.[126] In such contexts, the person’s interests and preferences are at risk of being dismissed due to their limited opportunities for a full recovery. In the worst scenarios, healthcare practitioners may fail to elicit the person's preferences, frustrate their attempts to participate in decisions about their care, and reduce them to a set of symptoms to be managed, rather than seeing them as a person whose views and goals are important. Even – and perhaps particularly – significant closeness to death must not be allowed to supersede this vital aspect of what it means to be human.[127]

Person-centred care and an emphasis on preserving the person’s dignity and legacy have been shown to increase a sense of personal dignity for this group of vulnerable people.[128] In the context of palliative care, dignity consists of three main dimensions which define the relationship between persons seeking care and healthcare professionals:

1. Illness-related concerns, related to symptoms of physical and psychological distress that threaten the person’s sense of dignity;
2. Concerns with preserving dignity, such as feeling a sense of continuity with the self before the illness, feeling a sense of pride, and being hopeful;

3. Concerns with the social aspects of dignity, such as perceiving social support and avoiding feeling like a burden to others.[129]

All three dimensions of dignity are often compromised in psychiatry and palliative care.[130] In a recent discussion of lived experience of dignity, hospitals have been described as ‘bureaucratic, commercialized, and impersonal places’ which threaten the dignity of healthcare providers and users alike.[131] Healthcare professionals experience increasing workloads and demands on their time, inadequate resources, and uncertainty about the best way to approach care within these constraints. People in palliative care may be treated with rudeness, indifference, and condescension. They may have their testimonies dismissed and their preferences disregarded. This results in practices characterised by intrusiveness, objectification, unnecessary labelling, contempt, discrimination, and revulsion.[132] These challenges to dignity and agency often have marked epistemic dimensions that the literature on epistemic injustice can illuminate.

To reduce these threats, the therapeutic relationship should be able to convey respect and hope, and the sense that the person will not be abandoned. In particular, it is important that palliative care for people with serious mental illness aims for adequate pain and symptom control, maintenance of function, enhancement of quality of life, support for relationships, and the possibility of dying with dignity. For this to happen, services for somatic and mental illness need to be well integrated and there needs to be continuity of care, interdisciplinary and multidisciplinary teamwork, communication, and outreach into community agencies and shelters. Cross-training in palliative care and mental health is essential to achieve this integration.[133]

Some optimism comes from the success of dignity-oriented interventions, such as Dignity Therapy, that can be successfully applied in several clinical settings; for example, people with serious mental illness who are receiving end of life or palliative treatment, and people affected by chronic disorders.[134] Dignity Therapy has been developed as a ‘brief, empirically based therapy that offers participants an opportunity to reflect upon crucial existential and relational issues and review aspects of their lives that they wish to be remembered’.[135] Evidence suggests that it improves quality of life, supports the sense of meaning and purpose, and reduces demoralization.[136] Dignity Therapy also helps people at the end of life to prepare a legacy of memories, and share words of love for significant others.

More evidence needs to be gathered on the prevalence and risk of epistemic injustice in persons suffering concurrently from cancer and serious mental illness. As part of project EPIC, we intend to investigate the experience of people receiving care in this context, with special attention to those who receive palliative care. Our aim is to build on what we already know to develop a more accurate map of problems and offer some initial solutions.

From the existing literature, three conclusions can be drawn:

1. Healthcare institutions need to provide better-integrated care for people who live with both somatic and mental illness. This is pressing given the prevalence of the phenomenon. Just focusing on cancer, 35-40% of patients have a diagnosable psychiatric condition and over 20% of patients develop depression.[137]

2. People with a cancer diagnosis and a serious mental illness, and people in palliative care, are at increased risk of having their testimonies dismissed, being objectified, and having their preferences ignored. This is due to the combined effects of mental health stigma and misleading assumptions about palliative care.

3. Dignity therapy and other dignity-oriented interventions have been shown to successfully counteract stigma and to improve quality of life in people receiving palliative care. Their potential to reduce the risk of epistemic injustice in the context of psycho-oncology should be further explored.

3.6. Dementia

Dementia is a condition that is highly stigmatized due to its associations with old age and cognitive decline, including difficulties with information processing, language skills and memory, and this stigmatisation has been shown to adversely affect the quality of people's lives.[138] People diagnosed with dementia may be at an elevated risk of experiencing epistemic injustice, as healthcare professionals frequently exclude them from information about, and authorship of, their care process.

This practice is based on the misleading assumption that dementia wholly compromises the capacity to contribute to knowledge exchanges.[139] As a result, people diagnosed with dementia are at risk of being excluded from shared decision-making and *objectified*, that is, treated as non-persons, and reduced to their diagnosis. Their testimonies are routinely regarded as unreliable or confused.[140] This leads to exclusion in diagnosis disclosure and advanced care planning and to the absence of shared decision making.

The increased vulnerability to epistemic injustice faced by people with dementia takes at least two forms. *Testimonial* injustice can occur when their credibility is unjustly diminished due to prejudices about cognitive decline, leading others to dismiss or undervalue their testimony. *Hermeneutical* injustice arises when society lacks, or resists developing, the conceptual and communicative resources necessary to understand and make sense of the lived experience of people with dementia. The latter is particularly problematic in dementia care, where behaviours and expressions that deviate from neurotypical norms are often pathologized rather than interpreted within the person's own framework of meaning.[141]

The epistemic injustice framework has not been applied to dementia until very recently, as it was believed that the dismissal of the testimonies of people living with dementia was not unfair, since dementia sufferers lose the capacity for both coherence and speech.[142] However, recent work has changed this assumption. First, dismissing the reports of people living with dementia or failing to elicit their preferences occurs frequently in the earlier stages of the illness, when they can still express themselves verbally and make themselves understood. Second, not all forms of expression that can contribute to knowledge exchanges need to be verbal. Paying attention and responding to non-verbal communication in the later stages of the illness enable people living with dementia to communicate with others and feel heard.[143]

The concept of 'living well' in chronic illness[144] underscores the importance of social health in maintaining the well-being of those affected and applies to dementia.[145] In recent studies, the key areas identified in a good life for people with dementia include engagement, an active lifestyle, positive social relationships, a good living environment, security, a positive outlook on life, the capacity to cope, independence, and purpose.[146] Ageism, defined as discrimination related to age, is already a significant barrier to social participation. In the context of dementia, further stigmatization can have negative consequences, impacting not only the person but also their family, healthcare services, and society at large. This has pervasive consequences, leading to lack of contact and engagement, exclusion from social exchanges, the loss of friendships, and loneliness [see case study 3.2].

Take the issue of diagnosis disclosure: people are generally thought to have a right to know about their health, and to decide whether they want to share such knowledge with others. But in the case of a dementia diagnosis these rights are violated: the disclosure of the diagnosis to the person is typically delayed and shared with caregivers from the start. Moreover, following a diagnosis, 'prescribed disengagement' is a source of discrimination and unnecessary exclusion: people may be told to give up their jobs and occupation and stay at home, when they are still capable of carrying on with valued aspects of their professional and social lives.[147]

The tendency to label the behaviours of people with dementia as expressions of the disorder ('challenging behaviours') is unnecessarily pathologising, and neglects the influence of social relationships and context in shaping such behaviours.[148] This labelling contributes to epistemic injustice, as people with dementia are no longer recognized for their active role in decision-making, nor seen as full participants in society, because expressions of their needs and preferences are taken to be symptoms of their dementia.[149] It is also a further instance of the spillover from well-demarcated symptoms to generalised epistemic distrust [see case study 3.4].

To reduce the harmful effects of the forms of epistemic injustice affecting people living with dementia, it is important to develop a capability-based approach: the presence of a diagnosis alone does not rule out the person's capacity to have interests and express preferences that matter to decisions about their future.[150] Dementia is not always an obstacle to people's active participation in social life. People living with dementia should feel valued, and have the opportunity to have pleasurable experiences, connect with others in a meaningful way, decide on things that matter to them, and preserve a sense of control over their lives.

The case study conducted as part of project EPIC aims at investigating the experience of people living with dementia, exploring issues of engagement, diagnosis disclosure, and uptake of behaviour in order to identify ways in which epistemic injustice affects their lives and can be addressed effectively. Initial research suggests that we need a more detailed account of the forms of epistemic injustice that people living with dementia are vulnerablised to, in order to conceive of effective strategies to reduce their harmful effects. Based on the notions of living well with illness and social health, current work suggests three promising strategies for amelioration:

1. Develop a better informed and more inclusive understanding of the capabilities of people living with dementia to support their interests, facilitate the social functions they find valuable, and create opportunities for them to preserve meaningful social interactions.
2. Avoid delaying the disclosure of a dementia diagnosis, enable people to participate in important decisions about their health, and include them in advance care planning.
3. Refrain from labelling behaviours of people with dementia as pathological, when such behaviours may just reflect the constraints and pressures of the surrounding environment and be an expression of unmet needs and frustrated preferences.

5. Recommendations

Understanding the determinants of health and their intersections requires the acknowledgment and study of a new theoretical framework, begun here: the epistemic determinants of health. Further research is needed to elaborate the myriad relationships between knowledge, health, and illness, and to situate them within other crucial determinants of health. Nonetheless, we have developed a series of recommendations, aligned with agendas on patient agency and voice, the democratisation of knowledge, and the co-creation of health research, which can offer a pathway to best practice. These involve ensuring that health service users – and other ill persons – are treated as credible sources of knowledge, both within healthcare encounters and in the broader systems of knowledge we have about illness and health.

- Work at the level of communication and access to information, ensuring that intelligible resources (including translations and easy read) are pro-actively offered, alongside practical assistance to service users to make engaging with healthcare systems simpler and more transparent.
- Develop and offer training aimed at heightening epistemic sensitivity, curiosity, and competence on the part of staff. This can aid healthcare professionals in establishing just and open interactions with service users, which validate their experiences, legitimise their service use, understand and recognise the medical relevance of their relationships and context, affirm their agency, and enable them to become co-authors of their treatment.
- Interventions at the level of metanarratives about health and illness; for example, around culpability for a particular condition, or the assumption that people suffering from a particular condition share traits which render them morally flawed or epistemically compromised (i.e. by habitual lying or pathological confusion).
- Interventions at the institutional level, which recognise how entrenched cultures and protocols perpetuate epistemic injustices (for example through opacity to the people they exist for) and consider how they might be resisted on a structural basis.
- Monitor, measure, and audit epistemic injustice through regulatory work. This might involve pulse-taking exercises, or building in discussion of whether proposed bureaucratic and policy changes are likely to reduce or heighten epistemic problems. This could also be applied in audits to public health campaigns, which can perpetuate metanarratives on health and illness which frame and amplify epistemic harms and inequalities.

6. Appendices

6.1. Project EPIC

EPIC: Epistemic Injustice in Health Care is a bold six-year research project funded by the Wellcome Trust [Grant no. 226603/Z/22/Z, 2023-2029], which addresses issues of epistemic injustice in healthcare contexts.

The concept of epistemic injustice in healthcare identifies epistemically unjust ways of conceiving of illness, treating ill persons, and allocating healthcare. This application to healthcare, initiated by the work of Havi Carel and Ian James Kidd, has inaugurated a new research area, with its own significant and growing literature.

However, much work remains to be done. There are understudied forms of epistemic injustice in healthcare; there is a need for detailed empirical study of various cases in healthcare and for empirical testing and validation of the concept; there is little research on how epistemic injustice could be ameliorated; and the required conceptual resources need to be integrated into wider discourses about healthcare.

EPIC will create a step-change by addressing these four areas:

1. fill knowledge gaps in existing epistemic injustice theory;
2. test the validity of the concept of epistemic injustice via six case studies of epistemic injustice in ill health;
3. develop strategies of amelioration;
4. introduce academic and clinical researchers and patient fora to epistemic injustice to develop its theoretical and practical possibilities.

EPIC aims to offer a new healthcare paradigm that will benefit ill persons, increase health equality, and improve healthcare.

6.2. The Agency-in-practice team

A multidisciplinary analysis of A&E mental health assessments

The Agency-in-practice team are a multidisciplinary collective of researchers, composed of young people with lived experience of mental health difficulties, psychologists, psychiatrists, and philosophers: Rachel Temple, Chris Sims, Jay Tuffnell, Carmen Lee, Catherine Fadashe, Josh Cottrell, and Michele Lim (The McPin Foundation); Lisa Bortolotti, Matthew Broome, and Sophie Tilston (University of Birmingham); Rose McCabe (City University London); and Shioma-Lei Craythorne and Michael Larkin (Aston University). The team has been working together for five years on two UKRI-funded research projects, 'Agency' and 'Agency-in-practice'. This work was supported by funding from UKRI under the 'MRC/AHRC/ESRC 'Adolescence, mental health and the developing mind: methodological innovation' scheme, grant no. MR/X003108/1: 'A new methodology linking interactional and experiential approaches, and involving young people as co-analysts of mental health encounters.' Four members of the Agency-in-practice team are also part of EPIC (McCabe, Larkin, Bortolotti, and Broome). In what follows, the agency-in-practice team share reflections on epistemic injustice and mental health treatment in UK Accident and Emergency (A&E) departments and Early Intervention for Psychosis (EIP) services.

What do we do?

In the Agency projects, we have been examining and discussing young people's experiences of seeking help for mental health difficulties. We analysed and discussed qualitative research data, working as a multi-disciplinary team of co-analysts, to understand and improve current responses to help-seeking in a medical setting. We analysed two kinds of data: video recordings of young people's mental health assessments at A&E departments, and retrospective research interviews conducted with young people who were being supported by Early Intervention for Psychosis (EIP) services. We examined video recordings from 21 psychosocial assessments conducted by professionals with young patients in the UK (aged 18–25), and a further 6 research interviews conducted with young people with first-episode psychosis. The interviews were carried out by Sophie Tilston, a clinical psychologist. The interview materials were developed in collaboration with the young people on our team. They were offered a 'menu' of different interview formats, all built around the same core questions, which explored their experiences of seeking and receiving support.

The video recordings were analysed using a form of Conversation Analysis (CA), and the interviews were analysed using a form of Interpretative Phenomenological Analysis (IPA). Both approaches were adapted and incorporated within a new methodology, Dialogical Co-Analysis, developed for the explicit purpose of enabling group analysis of qualitative data with young people with lived experience of help-seeking as co-analysts.[151]

In our discussion of these data, we focused on understanding several interlocking issues: how mental health professionals can support young people to be and feel understood when they seek help; how young people's sense of agency may be encouraged (or obstructed) during a clinical encounter; and how these communicative actions might subsequently affect young people's engagement with mental health services.

What have we seen?

In analysing our video recordings and interviews we noticed significant differences between young people's experiences of being seen for a generic, risk-focused, 'gateway' assessment (in the A&E data) and their experiences of being seen by a specialist, recovery-focused, outreach service (in the EIP data). In the former context, professionals' interactions with young people often seemed to have the unintended effect of steering young people away from professional support. This was because the threshold for accessing support in this setting appeared to be high and governed by an evaluation of immediate risk, even when other factors were assessed.[152] This is congruent with the picture painted by reviews of emergency department responses to young people's mental health crises.[153]

We noted instances which we interpreted as indicating that health professionals lacked curiosity about young people's distress and failed to invite them to elaborate on how they felt. When the young person described their feelings (‘I feel miserable’ or ‘My OCD won’t let me eat’), there was either minimal engagement with their reports or they were reconstrued in ways that could minimise the severity of their condition. The attitudes we found in the data were also observed by Bergen et al., who write:

> Multiple practices across the assessment built on each other to assert that the person was not suicidal, did not look or act like they were suicidal; that the person’s decision to attend the ED (emergency department) was not justified; that an overdose was impulsive and not intended to end life; asking why the person didn’t take a more harmful medication to overdose; that self-harming behaviors were not that serious and should be in the person’s control. Alternative characterizations were used to justify decisions, not to provide further support or referrals to specialist services. At times, these practices were also delivered when speaking over the patient.[154]

We take this to also mean that the young person's knowledge about their own difficulties was not seen as relevant.

We also saw instances of young people being effectively discouraged from pursuing further support, because professionals blamed them for the current dip in their mental health. For example, our analysis showed that young people were blamed for their current distress when they had failed to comply with a previous treatment plan, had self-medicated with drugs or alcohol, or had been unable to make use of other sources of support. We inferred that this would make the young help-seekers feel blamed, a therapeutically unhelpful effect. Implying blame also meant that important information which young people tried to share about why they had been struggling with these issues (such as bereavement, abuse, or fear for their safety) was not probed sufficiently. When analysing the data, we felt that young people's knowledge about their own difficulties was often overlooked or dismissed.

Practitioners also seemed to minimise difficulties that a young person shared, rather than pointing out the severity of their challenges. For example, young people were told that they actually seemed to be 'fine', since they were able to attend university a few days after seriously considering a suicide attempt, because they had plans to attend a party, or they had a supportive partner at home. Sometimes this minimisation was underscored by what we considered to be condescending tones, or the inappropriate use of humour ('I bet you wish you hadn't come here now'). In some cases we felt that the young person's knowledge about the context of their difficulties was distorted and used against them. This was in contrast to examples of better practice, where practitioners showed that they had listened and provided young people with constructive feedback which reflected this (e.g. 'You did exactly the right thing [by coming here] today').[155]

We also saw an instance where potential treatments were proposed, but where practitioners failed to explain to the young person what was involved, or to explore their views or concerns about the treatment option. In this case, the person was not invited to participate in decision making that impacted their health journey. We interpreted further examples in the data as indicating that health professionals dismissed emotions, at times achieved by tone of voice and body language rather than the words themselves, indicating impatience or that precious time was being wasted. For example, in one interaction, a university student had expressed his struggles with suicidal ideation to the healthcare professionals. The tone of voice used by the healthcare professionals to respond to the young person was dismissive, sarcastic, and lacked warmth. The young person's affective state was discounted as irrelevant or uninformative [see concept 2.5].

In many of the instances within the 21 videos we analysed, knowledge and insight brought to the consultation by the young person was excluded from it. Our team concluded that this exclusion of young people's knowledge negatively impacted on their care and wellbeing.

How does epistemic injustice hamper young people's need to be understood and make their own choices?

As a determinant of good mental health, knowledge - about oneself, and about mental health - is demonstrably important, especially when things go awry and we need to seek help. Public health approaches to the youth mental health crisis reflect this understanding. They have tended to focus on two elements: improving young people's mental health literacy (through various forms of psychoeducation) and encouraging young people to share their worries and concerns ('It's good to talk').

When young people respond to these initiatives by acting on their mental health knowledge, to seek help and share their worries, it is important that they receive an appropriate response.

When they are treated as if their experiences do not matter and their perspectives do not count, this undermines mutual trust and knowledge exchange, and reduces the likelihood that young people will seek help in the future.

Everyone is an expert in their own experiences, but as we have seen, young people are not always recognised as such in their interactions with mental health services. Feeling that their views do not count may discourage young people from sharing information, and from sharing what is troubling them. This undermines the purpose of assessment: it may limit the amount of information available to healthcare professionals for diagnosis and identification of meaningful support. Mutual understanding and trust are important for joint action. Mental health care is most likely to be experienced as helpful and humane when it is provided collaboratively, rather than coercively. In situations like those we have studied, where young people are actively seeking help, it ought to be possible to work collaboratively. Without understanding the care they are being offered, and while they do not feel understood, young people are unlikely to trust services.

What does 'good practice' look like?

A fair and successful interaction seeks to understand young people's distress in context, and to incorporate young people's knowledge into a form of care which supports their agency without blaming them. Even though our A&E data were largely characterised by insights into what not to do, there were still examples of good practice. In more successful interactions, we observed the empathy of healthcare professionals. Good practice validated the young person’s emotions and recognised that their mental health difficulties were being taken seriously. In these instances, practitioners listened actively and demonstrated an understanding of the severity of the issues faced by young people through small comments (e.g. ‘I’m so sorry you experienced that’), which indicated their attention and care.

Supportive and empathetic practice extended to body language and paralinguistic communication: by showing that one is listening and paying close attention, for example. Good practice involved health professionals facing the young person with open body language and not ‘communicating over’ them. Professionals who needed to communicate with each other during the interaction did so explicitly, and communicated to the young person beforehand what was happening and why. This created a space where the young person felt they were being listened to, and that they could talk about their experiences without judgement.

In our interview studies about EIP services, young people shared examples of good practice which included providing consistent care (professional support was valued because professionals kept showing up, demonstrating their trustworthiness), being patient and repeating the offer of support (young people sometimes needed time before they were ready to take up the offer of a specific kind of support), and being curious about what was important to the young person (and then acting on it to help the young person to meet those needs). The importance of relationships and knowledge in shaping young people's access to - and benefit from - EIP services is congruent with the results of a recent meta-synthesis study.[156] Young people referred to health professionals as acting like 'teachers', 'family', and 'mentors.' In these instances, good practice was supportive and guiding, but it consistently encouraged the young person to exercise greater agency as their recovery progressed, with the aim of leaving them confident to continue without support in the longer term. Repeatedly, our research emphasised the contrasts between one-off interactions within the high-stress and time-poor A&E environment and the specialised and ongoing EIP service, demonstrating how epistemic exchanges are scaffolded by institutional contexts, procedures, and resources.

6.3. Further resources

EPIC project website, including staff and collaborator profiles, case studies, talks, events, and publications: https://epistemicinjusticeinhealthcare.org/

EPIC blog: https://epistemicinjusticeinhealthcareproject.blogspot.com/

The Agency Project: https://mcpin.org/project/agency/

McPin Foundation, How to give young people agency in mental health: https://mcpin.org/how-to-give-young-people-agency-in-mental-health/

The Philosophy Garden: https://sites.google.com/view/the-philosophy-garden/home

Beyond Voice [case study 3.1]: https://beyondvoice.blogs.bristol.ac.uk/

Epistemic injustice and illness: an online bibliography curated by Ian James Kidd: https://ianjameskidd.weebly.com/epistemic-injustice-and-illness-bibliography.html

Bortolotti, L. (ed.) 2025. *Epistemic Justice in Mental Healthcare: Recognising Agency and Promoting Virtues Across the Life Span*. Cham: Palgrave Macmillan. Open access book available here: https://link.springer.com/book/10.1007/978-3-031-68881-2.

Kidd, I.J., Pohlhaus Jr, G., and Medina, J. (eds). 2019. *The Routledge Handbook on Epistemic Injustice*. New York: Routledge. https://www.routledge.com/The-Routledge-Handbook-of-Epistemic-Injustice/Kidd-Medina-PohlhausJr/p/book/9780367370633.

6.4. Contributor biographies and expertise

EPIC Principal Investigator

Professor Havi Carel, Philosophy, University of Bristol.

Havi Carel is Professor of Philosophy at the University of Bristol. She currently leads EPIC, a Wellcome Trust Discovery Award, on epistemic injustice in health care. She previously held a Wellcome Trust Senior Investigator Award, leading a five-year project, the Life of Breath. She was awarded the Health Humanities' Inspiration Award 2018 for her work on the project. Havi is the author of *Illness* (3rd edition 2018), shortlisted for the Wellcome Trust Book Prize, *Phenomenology of Illness* (2016), and of *Life and Death in Freud and Heidegger* (2006). She writes about the embodied experience of illness, epistemic injustice in healthcare, vulnerability, wellbeing within illness, transformative experience, death, and on the experience of respiratory illness.

Report Lead Author

Dr Fred Cooper, Law, University of Bristol.

Fred is a historian of medicine with a primary focus on the history, philosophy, and politics of loneliness. He works in the University of Bristol's Law School, and leads an EPIC case study on loneliness, epistemic injustice, and the history of knowledge. His work spans the history of medicine, loneliness studies, shame, public health, and the critical medical humanities. He is the author (with Luna Dolezal and Arthur Rose) of *COVID-19 and Shame: Political emotions and public health in the UK* (Bloomsbury, 2023); editor (with Des Fitzgerald) of *Knowing COVID-19* (Manchester University Press, 2024); and a member of the advisory group for the Campaign to End Loneliness. He can be reached at fred.cooper@bristol.ac.uk.

EPIC Co-Investigators

Professor Lisa Bortolotti, Philosophy, University of Birmingham; Neurosciences and Rehabilitation, University of Ferrara. Lisa's work is in the philosophy of the cognitive sciences and she is especially interested in belief, agency, rationality, and mental health. She is the author of *Why Delusions Matter* (Bloomsbury 2023) and the editor of *Epistemic Justice in Mental Healthcare* (Springer 2025, open access). Lisa is also the editor in chief of *Philosophical Psychology*. Lisa can be reached at l.bortolotti@bham.ac.uk.

Professor Matthew Broome, Institute for Mental Health, University of Birmingham.

Matthew is Chair in Psychiatry and Youth Mental Health, and Director of the Institute for Mental Health at the University of Birmingham. Matthew is also Honorary Consultant Psychiatrist to the East Birmingham Early Intervention in Psychosis Team, Birmingham Women's and Children's NHS Foundation Trust. He has a PhD in Psychiatry from the Institute of Psychiatry, University of London, and a PhD in Philosophy from the University of Warwick. Matthew's research interests include youth mental health, the prodromal phase of psychosis, delusion formation, phenomenology, and the philosophy of psychiatry. His research is funded by Wellcome, MRC, NIHR, Wolfson and the EU. Matthew can be reached at m.r.broome@bham.ac.uk.

Dr Ian James Kidd, Philosophy, University of Nottingham.

Ian is an Associate Professor of Philosophy at the University of Nottingham. His research includes the philosophy of healthcare, philosophy and phenomenology of somatic and psychiatric illness, philosophy of science, and epistemic injustice studies. With Prof Havi Carel, he initiated the study of epistemic injustices in relation to illness and healthcare and, with Prof Jose Medina and Prof Gaile Pohlhaus, Jr., co-edited *The Routledge Handbook to Epistemic Injustice* (2017). Ian can be reached at ian.kidd@nottingham.ac.uk.

Professor Sheelagh McGuinness, Law, University of Bristol.

Sheelagh McGuinness is Professor of Law in the Centre for Health, Law, and Society at the University of Bristol Law School in the United Kingdom. She researches and publishes in the areas of health and reproduction. Her previous research projects have examined abortion, reproductive loss, and best interest decision making in healthcare. Sheelagh is a member of the Board of Trustees of the British Pregnancy Advisory Service (2019-2024) having previously been a member of their Research and Ethics Committee. She has in the past been a member of the Irish National Screening Advisory Service, the Independent Ethics and Governance Council of UK Biobank, and the Medical Ethics Committee of the Royal College of General Practitioners.

Researchers, collaborators, and specialist staff

Professor Martino Belvederi Murri, Neurosciences and Rehabilitation, University of Ferrara.

Martino is Associate Professor at the Institute of Psychiatry and Director of the School of Specialization in Psychiatry, working as a clinical psychiatrist in the Acute Psychiatric Inpatient Unit. His research integrates clinical psychiatry with advanced statistical modelling and computational psychiatry, focusing on late-life depression, early psychosis, and psychosomatics. He has a specific interest in depression phenotyping, demoralization, psychosis outcomes, physical activity interventions, cognitive factors, and cannabis use.

Dr Michael Bresalier, History, University of Swansea.

Michael is a historian of modern medicine and global health at Swansea University and specialist investigator on EPIC. He leads an EPIC case study on the history and epistemic bases of tuberculosis (BCG) vaccination policies in Britain that selectively vaccinate infants in ethnic minority communities. His research interests are broadly in the production, legitimisation, circulation, and consequences of biomedical knowledge and public health policy, with particular focus on infectious diseases. His recent book on *Modern Flu* (Palgrave 2023) tackles these issues. Michael is co-director of the Medical Humanities Research Centre at Swansea and serves as an external evaluation expert for the Office of Evaluation of the United Nations Food and Agriculture Organization, for whom he recently co-authored an evaluation of the organization's One Health programme.

Dr Eleanor A. Byrne, Philosophy, University of Nottingham.

Eleanor is a philosopher working on EPIC. She specialises in the philosophy of emotion and phenomenology in chronic health conditions. She has conducted theoretical and empirical phenomenological studies into experiences of CFS/ME, Long Covid and Functional Neurological Disorder (especially functional tics and seizures). She can be contacted at ellie.byrne@nottingham.ac.uk.

Lara Calabrese, Psychology, University of Bologna.

Lara is a psychologist and research fellow at the University of Bologna (Italy). She is a member of the Research group on Psychosocial Interventions in Aging and Dementia (GRIPIDEM), working on a research project aimed at investigating epistemic injustice in the experience of people living with dementia. In 2023 she obtained a master's degree in Geropsychology for Longevity and Dementia from the University of Padua (Italy). She is currently attending a school of specialization in psychotherapy.

Professor Rabih Chattat, Psychology, University of Bologna.

Rabih Chattat is full Professor of Clinical Psychology at the University of Bologna and member of the board of INTERDEM, a European research network on psychosocial interventions in dementia care. His main research topics are aging and dementia. He focuses on interventions and studies aimed to promote wellbeing and social health for people with dementia and their caregivers along the trajectory of the disease from diagnosis to end of life. He is a partner in several international and national projects regarding the development of training tools for caregivers, the implementation of interventions, the analysis of the role of social health in the course of the disease and its impact on wellbeing.

Dr Dan Degerman, Philosophy, University of Bristol.

Dan is a Research Fellow in the Department of Philosophy at the University of Bristol, where he leads the EPIC case study on silence and epistemic injustice in bipolar, and the AHRC project 'Beyond Voice' [AH/Y001598]. His research interests lie at the intersection of the philosophy of mental health, emotions, and political freedom. He is the author of *Political Agency and the Medicalisation of Negative Emotions* (Edinburgh University Press, 2022), and the editor of *COVID-19 and the Politics of Fear* (Bristol University Press, 2024).

Professor Luigi Grassi, Neurosciences and Rehabilitation, University of Ferrara, and Integrated Department of Mental Health and Pathological Addiction, S. Anna University Hospital and Local Health Trust, Ferrara.

Luigi is Professor of Psychiatry at the University of Ferrara. His research interests cover the areas of Consultation-Liaison Psychiatry and Psychosomatic Medicine, Psycho-oncology, Psychotherapy, Clinical Psychiatry and Rehabilitation Psychiatry. He is the author of *Delirium: Acute Confusional States in Palliative Medicine* (Oxford University Press, 2011); *Clinical Psycho-oncology: An International Perspective* (Wiley, Chichester, 2012); and *Person-centered approach to recovery in medicine* (Springer, Berlin, 2019).

Professor Elisabetta Lalumera, Life Quality Studies, University of Bologna.

Elisabetta is an Associate Professor of Philosophy at the University of Bologna, associate researcher at the University of Johannesburg, and co-director of the Centre for Philosophy of Medicine, Epidemiology, and Public Health (Durham University and Johannesburg University). Her research applies philosophical analysis to conceptual and methodological issues in contemporary Western medicine, psychiatry, and psychology. She has published on concepts of health, disease, and mental disorder, medical nosology, the role of values and moralization in medical research, and specific issues in diagnostic imaging. Her monograph *Health, Well-Being, and Quality of Life – A Philosophical Analysis* is forthcoming with Palgrave Macmillan. Her interests also extend to metaphilosophy and the ethics of health communication.

Dr Alice Monypenny, Philosophy, University of Nottingham.

Alice is a research fellow in the Department of Philosophy exploring practices of testimonial smothering and resource sharing within patient communities. Her previous research explored safe spaces in educational settings and their role in promoting positive epistemic development. Her research interests also include feminist philosophy, virtue epistemology, and critical disability studies.

Dr Kathleen Murphy-Hollies, Philosophy, University of Birmingham.

Kathleen is a research fellow in the department of Philosophy at the University of Birmingham. As a part of EPIC, she is researching how epistemic injustice affects the construction of self-knowledge, as well as how to think about the rationality and meaning of delusions. More generally, she is interested in philosophy of cognitive science, social epistemology, and virtue ethics.

Dr Jodie Russell, Institute for Mental Health, University of Birmingham.

Jodie is a research fellow in the School of Psychology, working with co-investigators Matthew Broome and Lisa Bortolotti to investigate cases of epistemic injustice among young people with psychosis. Her background is in philosophy, with specialisation in phenomenology which she uses alongside qualitative methods to analyse the lived experience of young people. Her work also incorporates critical approaches, such as feminist philosophy, to explore the ethical and political implications of scientific research in mental health. Jodie can be reached at j.l.russell@bham.ac.uk.

Jude Williams, Institute for Mental Health, University of Birmingham.

Jude provides administrative support to EPIC and has a background in project management and European policy. She is particularly interested in social justice and wellbeing and volunteers for the Choir With No Name, a choir for people impacted by homelessness and marginalisation. Through the power of collective singing and support, members are enabled to achieve other positive life impacts such as improved mental health, finding work and securing more stable accommodation. Jude can be reached at j.williams.7@bham.ac.uk.

Charlotte Withers, Philosophy, University of Bristol.

Charlotte is the project manager for EPIC. She has extensive experience working on complex, interdisciplinary research projects across the humanities, social sciences, and natural sciences, and holds a degree in English and Philosophy and a master’s in Philosophy, with a particular focus on the philosophy of science and medicine.

The Agency-in-practice team

Joshua Cottrell, The McPin Foundation.

Josh is a dental student at the University of Liverpool. As a member of the Agency project team, he is most interested in the role of mental health in the success of interactions between professionals and patients.

Dr Shioma-Lei Craythorne, Psychology, Aston University.

Shioma-Lei is a Senior Research Fellow and study co-ordinator for the Agency-in-practice project, based at Aston University. Her research interests include youth mental health, body image disturbances (including body dysmorphic disorder), and co-production using visual and phenomenological approaches.

Catherine Fadashe, The McPin Foundation.

Catherine is a mental health advocate, Trustee at Young Minds Matter and a young person advisor at The McPin Foundation and TEDx speaker. Catherine graduated from Birkbeck, University of London with a BA (Hons) in English Literature and Italian.

Professor Michael Larkin, Psychology, Aston University.

Michael Larkin is a parent (with experience of navigating health and care services), and a professor at Aston University (where he conducts qualitative research with young people to understand the relationships which help them to maintain their mental health). He is a member of the EPIC and Agency project research teams.

Professor Rose McCabe, Health Services Research and Management, City University of London.

Rose McCabe is a professor at City St George’s University of London. She works on improving communication and relationships in schools, hospitals and mental health services. She is a member of the EPIC and Agency project teams.

Chris Sims, The McPin Foundation.

Chris is a lived experience advisor for various projects and has direct experience with several different health care services. Chris has been part of the Agency-in-practice team since the beginning. Chris is also aspiring to become a mental health nurse and to use his personal experience to improve mental healthcare services for individuals in the future.

Jay Tuffnell, The McPin Foundation.

Jay is a politics student at the University of Cambridge with lived experience of interacting with young people's mental health services. They are a member of the YPAG on the Agency project.

Rachel Temple, The McPin Foundation.

Rachel Temple is a young adult with lived experience of accessing mental health services. She is Youth Public involvement in research manager at The McPin Foundation, a charity that exists to improve everyone's mental health through research informed and directed by expertise generated through lived experience.

References

---

[1] Coady, C. 2010. 'Two Concepts of Epistemic Injustice', *Episteme*, 7(2): 101-113. https://doi.org/10.3366/epi.2010.0001; Kurtulmus, F. and Irzik, G. 2017. 'Justice in the distribution of knowledge', *Episteme*, 14(2): 129-146. https://doi.org/10.1017/epi.2015.65; Irzik, G. and Kurtulmus, F. 2024. 'Distributive Epistemic Justice in Science', *The British Journal for the Philosophy of Science*, 75(2): 325–45; Carel, H. H., & Kidd, I. J. 2014. 'Epistemic injustice in healthcare: a philosophical analysis'. *Medicine, Health Care and Philosophy*, 17(4): 529-540. https://doi.org/10.1007/s11019-014-9560-2.

[2] Fricker, M. 2007. *Epistemic Injustice: Power and the Ethics of Knowing*. Oxford: Oxford University Press.

[3] Hookway, C. 2006. 'Epistemology and inquiry: The primacy of practice'. In *Epistemology Futures,* edited by Stephen Cade Hetherington. New York: Oxford University Press.

[4] Green, J. 2020. 'Epistemic Goods', *Southwest Philosophy Review*, 36(1): 187-198.

[5] McKenna, R. 2023. *Non-Ideal Epistemology*. Oxford: Oxford University Press.

[6] Carmona, C. 2024. 'Engaging Epistemically with the Other: Toward a More Dialogical and Plural Understanding of the Remedy for Testimonial Injustice'. *Episteme*, 21(3): 871-900.

[7] Watson, L. 2018. 'Educating for Good Questioning: a Tool for Intellectual Virtues Education', *Acta Analytica,* 33(3): 353-370.

[8] Wanderer, J. 2019. 'Varieties of Testimonial Injustice'. In *The Routledge Handbook on Epistemic Injustice,* edited by Ian James Kidd, Gaile Pohlhaus Jr & José Medina. New York: Routledge.

[9] Haenel, H., and Bratu, C. 2021. 'Varieties of Hermeneutical Injustice: A Blueprint', *Moral Philosophy and Politics*, 8(2): 331-350.

[10] Kidd, I.J., and Carel, H. 2016. 'Epistemic Injustice and Illness,' *Journal of Applied Philosophy*, 34 (2): 172-190; Kidd, I.J., and Carel, H. 2018. 'Healthcare Practice, Epistemic Injustice, and Naturalism', *Royal Institute of Philosophy Supplement,* 84: 1-23.

[11] Kidd, I.J., and Carel, H. 2021. 'The Predicament of Patients', *Royal Institute of Philosophy Supplement*, 89: 65-74.

[12] Ilana Ambrogi, I., Brito, L. & dos Santos, R.L. 2023. 'Epistemic Justice and Feminist Bioethics in Global Health', *Journal of Medical Ethics*, 49(5): 345-346.

[13] Peled Y. 2018. 'Language barriers and epistemic injustice in healthcare settings'. *Bioethics*, 32(6): 360–367. https://doi.org/10.1111/bioe.12435.

[14] Bullock, C.G. 2023. 'Experiencing "epistemic injustice" within transgender healthcare.' *Sexuality, Gender & Policy*, 6(1): 47–50. https://doi.org/10.1002/sgp2.12059.

[15] Eve Appeal. 2025. What adjustments can you ask for at your cervical screening? https://eveappeal.org.uk/news/what-adjustments-can-you-ask-for-at-your-cervical-screening/ (accessed 02/06/2025).

[16] Danan, E. R., Brunner, J., Bergman, A. et al. 2022. 'The Relationship Between Sexual Assault History and Cervical Cancer Screening Completion Among Women Veterans in the Veterans Health Administration'. *Journal of women's health*, 31(7): 1040–1047. https://doi.org/10.1089/jwh.2021.0237.

[17] Eve Appeal. What adjustments can you ask for at your cervical screening?

[18] Eve Appeal. What adjustments can you ask for at your cervical screening?

[19] Eve Appeal. What adjustments can you ask for at your cervical screening?

[20] NHS. 2024. Having cervical screening: An easy guide about cervical screening for women aged 25 to 64. https://www.gov.uk/government/publications/cervical-screening-easy-read-guide (accessed 02/06/2025).

[21] Macmillan Cancer Support. 2022. Cervical screening [smear test]. https://www.macmillan.org.uk/cancer-information-and-support/stories-and-media/booklets/cervical-screening-easy-read (accessed 02/06/2025).

[22] Eve Appeal. 2025. Information and tips on screening for trans and non-binary people. https://eveappeal.org.uk/information-and-advice/gynaecological-cancers/information-for-trans-men-and-non-binary-people/tips-for-your-screening-appointment/ (accessed 02/06/2025).

---

[23] Stroumsa, D., Raja, N.S., & Russell, C.B. 2024. ‘Reproductive Health in Trans and Gender-Diverse Patients: Trauma-informed reproductive care for transgender and nonbinary people’. *Reproduction*,168(6): e240054. https://doi.org/10.1530/REP-24-0054.
[24] Eve Appeal. 2025. Information and tips on screening for trans and non-binary people.
[25] Samulowitz, A., Gremyr, I., Eriksson, E., & Hensing, G. 2018. ‘"Brave Men" and "Emotional Women": A Theory-Guided Literature Review on Gender Bias in Health Care and Gendered Norms towards Patients with Chronic Pain’. *Pain research & management*. 6358624. https://doi.org/10.1155/2018/6358624.
[26] Barden, O., and Cook, T. 2021. ‘Learning Difficulties: Histories and Cultures’. *Journal of Literary & Cultural Disability Studies* 15(3): 263-267, 263. https://doi.org/10.3828/jlcds.2021.22.
[27] Raymond, N. 2025. Trump administration must restore health articles scrubbed for transgender mentions, judge rules. *Reuters,* May 23 (accessed 02/06/2025); McNamara, M., McLamore, Q., Meade, N., et al. 2024. A thematic analysis of disinformation in gender-affirming healthcare bans in the United States. Social Science & Medicine, 351. https://doi.org/10.1016/j.socscimed.2024.116943.
[28] Bergen, C., Bortolotti, L., Tallent, K. et al. 2022. ‘Communication in youth mental health clinical encounters: Introducing the agential stance’. *Theory & Psychology*, 32(5): 667-690. https://doi.org/10.1177/09593543221095079.
[29] Bortolotti, L. 2024. ‘The Ant and the Grasshopper: Does Biased Cognition Compromise Agency in the Case of Delusions and Conspiracy Theories?’. *Rev.Phil.Psych*. https://doi.org/10.1007/s13164-024-00760-x.
[30] Bortolotti, L., Malpass, F., Murphy-Hollies, K., et al. 2025. .Challenging Stereotypes About Young People Who Hear Voices’. In: Bortolotti, L. (eds) *Epistemic Justice in Mental Healthcare* (Cham: Palgrave Macmillan). https://doi.org/10.1007/978-3-031-68881-2_2.
[31] Bortolotti, L. (forthcoming). ‘Agential Epistemic Injustice in Clinical Interactions Is Bad for Medicine’, *Philosophy of Medicine*.
[32] Chattat, R., Trolese, S., Chirico, I. 2025. ‘Promoting Good Living and Social Health in Dementia’. In *Epistemic Justice in Mental Healthcare*, edited by Lisa Bortolotti. Cham: Palgrave Macmillan. https://doi.org/10.1007/978-3-031-68881-2_7.
[33] Bortolotti, L. and Broome, M.R. 2012. ‘Affective dimensions of the phenomenon of double bookkeeping in delusions’. *Emotion Review* 4(2): 187-191.
[34] Bortolotti, L. (ed.) 2025. *Epistemic Justice in Mental Healthcare*. Cham: Palgrave Macmillan. https://doi.org/10.1007/978-3-031-68881-2_2. p. ix.
[35] Heidegger, M. 1962 [1927]. *Being and time*. London: Blackwell; Merleau-Ponty, M. 2012 [1945]. *Phenomenology of perception*. New York: Routledge.
[36] Svenaeus, F. 2000. Das Unheimliche – Towards a phenomenology of illness. *Medicine, Health Care and Philosophy* 3: 3–16; Svenaeus, F. 2000. The body uncanny – Further steps towards a phenomenology of illness. *Medicine, Health Care and Philosophy* 3: 125–137.
[37] Pienkos, E., Englebert, J., Feyaerts, J., et al. 2023. ‘Situating phenomenological psychopathology: subjective experience within the world’. *Frontiers in Psychology*, 14. https://doi.org/10.3389/fpsyg.2023.1204174.
[38] Carel, H. and Kidd, I.J. 2021. ‘When Institutional Opacity Meets Individual Vulnerability: Institutional Testimonial Injustice’. *International Journal of Philosophical Studies*, 29(4): 473-496.
[39] Kidd IJ and Carel H. 2016. ‘Epistemic Injustice and Illness’. Journal of Applied Philosophy 3 (2): 172–190. https://doi.org/10.1111/japp.12172.
[40] Tekin, Ş. 2022. ‘Participatory interactive objectivity in psychiatry’, *Philosophy of Science*, 89(5): 1166-1175. Carel, H. 2016. *Phenomenology of Illness*. Oxford, Oxford University Press.
[41] Byrne, L., Happell, B., & Reid-Searl, K. 2015. ‘Lived experience practitioners and the medical model: worlds colliding?’ *Journal of Mental Health*, 25(3): 217–223. https://doi.org/10.3109/09638237.2015.1101428.
[42] Palafox-Harris, E. 2024. ‘Delusion and epistemic injustice’. *The Routledge Handbook of Philosophy of Delusion*. London: Routledge.
[43] Hofmann, J., Haerle, P. H., & Maatz, A. 2023. ‘What’s the Linguistic Meaning of Delusional Utterances? Speech Act Theory as a Tool for Understanding Delusions’. *Philosophical Psychology*. https://doi.org/10.1080/09515089.2023.2174424.
[44] Toombs, S. Kay. 1987. ‘The meaning of illness: A phenomenological approach to the ill person-physician relationship’. *Journal of Medicine and Philosophy*, 12(3):219-240.
[45] Toombs. ‘The meaning of illness’.
[46] Merleau-Ponty, M. 2014 [1945]. *Phenomenology of Perception*. Oxon: Routledge.
[47] Graedon, T. and Graedon, J. 2014. ‘Let patients help with diagnosis.’ *Diagnosis,* 1(1): 49-51.

---

[48] Spencer, L. J. 2023. ‘Hermeneutical Injustice and Unworlding in Psychopathology’. *Philosophical Psychology*. https://doi.org/10.1080/09515089.2023.2166821.

[49] Fricker. *Epistemic injustice.*

[50] Carel, H. 2012. ‘Phenomenology as a resource for patients’. *Journal of Medicine and Philosophy* 37 (2): 96–113.

[51] Kidd, I.J. 2019. ‘Pathophobia, Illness, and Vices’. *International Journal of Philosophical Studies*, 27.2: 286-306. https://doi.org/10.1080/09672559.2019.1612625.

[52] Kidd and Carel. ‘The Predicament of Patients’; Kidd, I.J. and Carel, H. 2025. ‘From Predicaments to Pathophobia: Non-ideal Theory Approaches to Philosophy of Illness’, Hänel, H.C. and Müller, J. (eds.) *Routledge Handbook of Non-Ideal Theory* (New York: Routledge), 352-366.

[53] Vickers, N. and Bolton, D. 2024. *Being Ill: On Sickness, Care, and Abandonment*. London: Reaktion Books.

[54] Rabin, D., & Rabin, P. L. 1983. The pariah syndrome: the social disease of chronic illness. *The Pharos of Alpha Omega Alpha-Honor Medical Society. Alpha Omega Alpha*, *46*(3), 37–40.

[55] Kidd. ‘Pathophobia, Illness, and Vices’.

[56] Kidd. ‘Pathophobia, Illness, and Vices’. 292

[57] Kidd. ‘Pathophobia, Illness, and Vices’. 294

[58] Kidd. ‘Pathophobia, Illness, and Vices’. 296

[59] Kidd. ‘Pathophobia, Illness, and Vices’. 299

[60] Kidd. ‘Pathophobia, Illness, and Vices’. 302

[61] Berrios, G. E. 1991. ‘Delusions as “wrong beliefs”: A conceptual history’. *The British Journal of Psychiatry*, 159(S14): 6–13.

[62] Jaspers, K. 1963. *General Psychopathology*. Manchester: Manchester University Press.

[63] Laing, R. D. 1960. *The Divided Self: An Existential Study in Sanity and Madness.* London: Penguin Books; Bentall, R. P. 1994. ‘Cognitive biases and abnormal beliefs: Towards a model of persecutory delusions’. In *The neuropsychology of schizophrenia*, edited by A.S. David and J. Cutting. UK: Erlbaum. Roberts, G. 1992). ‘The origins of delusion’, *British Journal of Psychiatry*, 161(3): 298–308.

[64] Garson, J. 2022. *Madness: A Philosophical Exploration*. Oxford: Oxford University Press.

[65] Gunn, R. and Bortolotti, L. 2018. ‘Can delusions play a protective role?’. *Phenomenology and the Cognitive Sciences,* 17(4): 813–833.

[66] Ritunnano, R. and Bortolotti, L. 2022. ‘Do delusions have and give meaning?’. *Phenomenology and the Cognitive Sciences*, 21(4): 949-968.

[67] Feyaerts, J., Kusters, W., Van Duppen, Z. et al. 2021. ‘Uncovering the realities of delusional experience in schizophrenia: A qualitative phenomenological study in Belgium’. *The Lancet Psychiatry,* 8(9): 784–796.

[68] Ritunnano, R., 2022. ‘Overcoming hermeneutical injustice in mental health: A role for critical phenomenology’. *Journal of the British Society for Phenomenology*, *53*(3), pp.243-260.

[69] Ritunnano, R. and Littlemore, J. 2024. ‘Delusion and meaning’, *The Routledge Handbook of Philosophy of Delusion*. London: Routledge.

[70] Fricker. *Epistemic Injustice*.

[71] Bortolotti, L. and Murphy-Hollies, K. 2023. ‘Why we should be curious about each other’. *Philosophies*, 8(4), 71.

[72] Whitney, S. 2023. ‘Anger Gaslighting and Affective Injustice’, *Philosophical Topics*, 51(1): 27-62. https://muse.jhu.edu/article/931325.

[73] Salerno, J. M., & Peter-Hagene, L. C. 2015. ‘One angry woman: Anger expression increases influence for men, but decreases influence for women, during group deliberation’. *Law and human behavior*, 39(6): 581–592. https://doi.org/10.1037/lhb0000147.

[74] Whitney, S. 2018. ‘Affective intentionality and affective Injustice: Merleau-Ponty and Fanon on the Body Schema as a Theory of Affect’. *The Southern Journal of Philosophy*, 56(4): 488-515.

[75] Oredsson, A. F. 2023. ‘Women “out of order”: inappropriate anger and gender bias in the diagnosis of borderline personality disorder’. *Journal of Psychosocial Studies*, 1(aop), 1-14.

[76] Archer, A., & Mills, G. 2019. ‘Anger, affective injustice, and emotion regulation’. *Philosophical topics*, 47(2): 75-94.

[77] Byrne, E. A. 2024. ‘Affective scaffolding and chronic illness’. *Philosophical Psychology*, 37(4): 921-946.

[78] Dotson, K. 2011. ‘Tracking epistemic violence, tracking practices of silencing’. *Hypatia*, 26(2): 236-257.

[79] Warman, J. 2023. ‘Testimonial smothering and domestic violence disclosure in clinical contexts’. *Episteme*, 20(1): 107-124.

---

[80] Sakakibara, E. 2023. ‘Epistemic injustice in the therapeutic relationship in psychiatry’. *Theoretical medicine and bioethics*, 44(5): 477–502.

[81] Dotson. ‘Tracking epistemic violence, tracking practices of silencing’.

[82] Goldberg, D. S. 2017. ‘Pain, objectivity and history: understanding pain stigma’. *Medical Humanities*, 43(4): 238-243.

[83] For example, see Neville-Jan, A. 2003. ‘Encounters in a world of pain: An autoethnography’. *The American journal of occupational therapy*, 57(1): 88-98.

[84] O'Mahony, B., Nielsen, G., Baxendale, S. et al. 2023. ‘Economic cost of functional neurologic disorders: a systematic review’, *Neurology*, 101(2): e202-e214.

[85] Edwards, M. J., Yogarajah, M., & Stone, J. 2023. ‘Why functional neurological disorder is not feigning or malingering’, *Nature Reviews Neurology*, 19(4): 246-256.

[86] Degerman, D., Carel, H. and Kidd, I.J. In press. ‘Silence and epistemic injustice’, *Royal Institute of Philosophy Supplement*.

[87] Kidd, I. J., Spencer, L., & Carel, H. 2023. ‘Epistemic injustice in psychiatric research and practice’. *Philosophical Psychology* (early online access). https://doi.org/10.1080/09515089.2022.2156333.

[88] Degerman, D. 2025. ‘Silence, depression, and bodily doubt: toward a phenomenology of silence in psychopathology’, *Philosophical psychology*, 38(1): 126-149. https://doi.org/10.1080/09515089.2024.2354447.

[89] Solomon, A. 2015. *The noonday demon* (2nd ed: Vintage).

[90] Sul, J.R. 2025. ‘The structure of silence in depression’, *Synthese*, 205(77). https://doi.org/10.1007/s11229-025-04933-8.

[91] Cheney, L. 2009. *Manic: A memoir*. New York: William Morrow & Company.

[92] Degerman, D. 2025. ‘Silence as epistemic agency in mania’. *Medicine, Health Care and Philosophy* (early online access). https://doi.org/10.1007/s11019-025-10256-9.

[93] Degerman, D. 2024. ‘Experiences of Silence in Mood Disorders’. *Erkenn*, 89: 2783–2802. https://doi.org/10.1007/s10670-022-00652-5.

[94] Nakane, I. 2012. ‘Silence’. In *The Handbook of Intercultural Discourse and Communication,* edited bu C. Bratt Paulston, S.F. Kiesling, and E.S. Rangel. London: Wiley-Blackwell.

[95] Kidd, I.J., and Carel, H. 2018. ‘Healthcare Practice, Epistemic Injustice, and Naturalism’. *Royal Institute of Philosophy Supplement*, 84: 1-23.

[96] Froom, H., Loughran, T., Mahoney, K., and Payling, D. 2024. *‘Everyday health’, embodiment, and selfhood since 1950*. Manchester: Manchester University Press.

[97] Cooper, F. 2024. ‘Solitude is not thrust upon any lovable person’: loneliness, shame and the problem (of) personality. *Journal of Psychosocial Studies*, 17(1): 28-45. https://doi.org/10.1332/14786737Y2023D000000004.

[98] Kidd and Carel. ‘Healthcare Practice, Epistemic Injustice, and Naturalism’.

[99] Uher, J. 2023. ‘What's wrong with rating scales? Psychology's replication and confidence crisis cannot be solved without transparency in data generation’. *Social and Personality Psychology Compass*, 17(5): e12740. https://doi.org/10.1111/spc3.12740.

[100] Victor, C.R. 2021. ‘The Languages of Loneliness: Developing a Vocabulary for Researching Social Health.’ In *Loneliness and the Built Environment,* edited by Fernando Nieto and Rosana Rubio. Tampere: Tampere University Occasional Papers, 51-72, 58.

[101] Armstrong, N. Byrom, N. 2024. ‘An anthropological critique of psychiatric rating scales’. *BJPsych Advances*, 31: 1-9.

[102] Nuwarda RF, Ramzan I, Weekes L, Kayser V. 2022. ‘Vaccine Hesitancy: Contemporary Issues and Historical Background.’ *Vaccines*, 10:1595.

[103] Decoteau, C.L. and Sweet, P.L. 2024. ‘Vaccine Hesitancy and the Accumulation of Distrust.’ *Social Problems*, 71(4): 1231–1246. https://doi.org/10.1093/socpro/spad006.

[104] Blume, S. 2017. *Immunization: How Vaccines Became Controversial*. London: Reaktion.

[105] Goldenberg, M. J. 2021. *Vaccine Hesitancy: Public Trust, Expertise, and the War on Science* Pittsburgh: University of Pittsburgh Press.

[106] Leach, M. and J. Fairhead. 2007. *Vaccine Anxieties: Global Science, Child Health and Society*. London: Earthscan.

[107] Abimbola, S. 2021. ‘The uses of knowledge in global health’, *BMJ Global Health* 2021; Koum Besson, E.S. 2022. ‘How to identify epistemic injustice in global health research funding practices: a decolonial guide’, *BMJ Global Health* 7:e008950. https://doi.org/10.1136/bmjgh-2022-008950.

[108] Richardson, E.T. 2019. ‘On the Coloniality of Global Public Health’, *Medicine Anthropology Theory*, 6(4). https://doi.org/10.17157/mat.6.4.761; Bhakuni, H., and Abimbola., S. 2021. ‘Epistemic Injustice in Academic Global Health’, *The Lancet Global Health*, 9(10): e1465–e70.

---

[109] Gagné-Julien, A. M. 2022. 'Medicalization, Contributory Injustice, and Mad Studies', *Kennedy Inst Ethics J.* 32(4): 401-434.

[110] Zwerling, A., Behr, M.A., Verma, A, et al. 2011. 'The BCG World Atlas: A Database of Global BCG Vaccination Policies and Practices.' *PLoS Med* 8(3): e1001012. https://doi.org/10.1371/journal.pmed.1001012.

[111] 'Criteria for discontinuation of vaccination programmes using Bacille Calmette-Guerin (BCG) in countries with a low prevalence of tuberculosis. A statement of the International Union Against Tuberculosis and Lung Disease.' 1994. Tuber Lung Dis., 75(3): 179-80. https://doi.org/10.1016/0962-8479(94)90003-5; World Health Organization. 2004. 'BCG vaccine'. WHO position paper. *Wkly Epidemiol Rec*., 79(4): 27-38.

[112] Samra, R. 2023. 'Beyond epistemic injustice: When perceived realities conflict', *Harvard Review of Psychiatry*, 31(5): 223-225.

[113] Carel, H. and Györffy, G. 2014. 'Seen but not heard: children and epistemic injustice'. *The Lancet*, 384(9950), 1256-1257. https://doi.org/10.1016/s0140-6736(14)61759-1.

[114] Baumtrog, M.D. and Peach, H. 2019. 'They can't be believed: children, intersectionality, and epistemic injustice'. *Journal of Global Ethics*, 15(3): 213-232.

[115] Carel and Györffy. 'Seen but not heard'.

[116] Greenblatt, A., Lee, E., Ashcroft, R. and Muskat, B. 2024. 'Epistemic justice and injustice among youth with mental health concerns'. Children & Society, 38(4): 1039-1058; see also Houlders, J.W., Bortolotti, L. and Broome, M.R. 2021. 'Threats to epistemic agency in young people with unusual experiences and beliefs', *Synthese*, 199(3): 7689-7704.

[117] Bortolotti et al. 'Challenging Stereotypes About Young People Who Hear Voices'.

[118] Belvederi Murri, M., Folesani, F., Nanni, M.G., Grassi, L. 2025. 'Reacting to Demoralization and Investigating the Experience of Dignity in Psychosis: Reflections from an Acute Psychiatric Ward'. In *Epistemic Justice in Mental Healthcare*, edited by Lisa Bortolotti. Cham: Palgrave Macmillan. https://doi.org/10.1007/978-3-031-68881-2_3.

[119] Collins, P. H., 1990. 'Black feminist thought in the matrix of domination', *Black feminist thought: Knowledge, consciousness, and the politics of empowerment*, 138, 221-238; Crenshaw, K. 1991. 'Mapping the Margins: Intersectionality, Identity Politics, and Violence Against Women of Color'. *Stanford Law Review*, 43(6): 1241-1299; Essed, P. 1991. 'Understanding Everyday Racism: An Interdisciplinary Theory.' In *Sage Series on Race and Ethnic Relations*, 2, edited by John H. Stanfield II. London: Sage.

[120] Public Health England. 2016. 'Psychosis data report', [Online] Available: https://www.gov.uk/government/publications/psychosis-data-report. [Accessed 29/10/2024]

[121] Purdie-Vaughns, V., and Eibach, R.P. 2008. 'Intersectional invisibility: The distinctive advantages and disadvantages of multiple subordinate-group identities'. *Sex roles,* 59: 377-391.

[122] Houlders et al. 'Threats to epistemic agency in young people with unusual experiences and beliefs'.

[123] Grassi, L. and Riba, M. 2012. *Clinical Psycho-Oncology: An International Perspective*. Blackwell, UK, page 3.

[124] Grassi, L., Cruciata, M., Belvederi Murri, M., et al. 2025. 'Preserving Dignity and Epistemic Justice in Palliative Care for Patients with Serious Mental Health Problems'. In *Epistemic Justice in Mental Healthcare*, edited by Lisa Bortolotti. Cham: Palgrave Macmillan. https://doi.org/10.1007/978-3-031-68881-2_6.

[125] Alcalde, J., & Zimmermann, C. 2022. 'Stigma about palliative care: Origins and solutions.' *Ecancermedicalscience, 16*, 1377. https://doi.org/10.3332/ecancer.2022.1377

[126] Lawrence, D., & Kisely, S. 2010. 'Inequalities in healthcare provision for people with severe mental illness'. *Journal of Psychopharmacology,* 24(4): 61–68.

[127] Grassi, L., & Riba, M. 2020. 'Cancer and severe mental illness: Bi-directional problems and potential solutions'. *Psychooncology*, 29(10): 1445–1451.

[128] Mezzich, J. E., Botbol, M., Christodoulou, G. N., et al. (eds). 2016. *Person centered psychiatry*. Springer.

[129] Chochinov, H. M., Hack, T., McClement, S., et al. 2002. 'Dignity in the terminally ill: A developing empirical model'. *Social Science & Medicine*, 54: 433–443.

[130] Grassi, L., Chochinov, H., Moretto, G., Nanni, M.G. 2019. 'Dignity-Conserving Care in Medicine'. In: Grassi, L., Riba, M., Wise, T. (eds) *Person Centered Approach to Recovery in Medicine. Integrating Psychiatry and Primary Care*. Springer, Cham. https://doi.org/10.1007/978-3-319-74736-1_6.

[131] Pellegrino, E. 2008. 'The lived experience of human dignity', *Human dignity and bioethics: Essays commissioned by the President's Council of Bioethics*, pp. 513–540.

---

[132] Kidd. 'Pathophobia, Vices, and Illness'.
[133] Callaway, C. A., Corveleyn, A. E., Barry, M. J., et al. 2021. 'Lessons learned: Building a coalition to advance equity in cancer and mental health care'. *Psychooncology*, 30(12): 2087–2091.
[134] Grassi, L., Nanni, M.G., Riba, M., Folesani, F. 2024. 'Dignity in Medicine: Definition, Assessment and Therapy'. *Current Psychiatry Reports*, 26(6): 273-293. https://doi.org/10.1007/s11920-024-01506-3.
[135] Grassi, L., Nanni, M.G., Caruso, R., et al. 2022. 'A comparison of Dignity Therapy narratives among people with severe mental illness and people with cancer.' *Psychooncology*. 2022; 31(4): 676-679. https://doi.org/10.1002/pon.5913.
[136] Fitchett, G., Emanuel, L., Handzo, G., Boyken, L., Wilkie, D.J. 2015. 'Care of the human spirit and the role of dignity therapy: a systematic review of dignity therapy research'. *BMC Palliative Care*, 14: 8. https://doi.org/10.1186/s12904-015-0007-1.
[137] Fernando, A., Tokell, M., Ishak, Y., Love, J., Klammer, M., & Koh, M. 2023. Mental health needs in cancer - a call for change. *Future Healthcare Journal*, 10(2):112-116. https://doi.org/10.7861/fhj.2023-0059.
[138] Evans, S. C. 2018.' Ageism and dementia'. In L. Ayalon & C. Tesch-Römer (Eds.), *Contemporary perspectives on ageism: Vol. 19. International perspectives on aging* (pp. 263–275). Berlin Press; Kang, H., & Kim, H. 2022. Ageism and psychological well-being among older adults: A systematic review. *Gerontology and Geriatric Medicine, 8*, 23337214221087023. https://doi.org/10.1177/23337214221087023.
[139] Kitwood, T. 1997. *Dementia reconsidered: The person comes first*. Open University Press, Buckingham, UK.
[140] Jongsma, K., Spaeth E., and Schicktanz S. 2017. 'Epistemic Injustice in Dementia and Autism Patient Organizations: An Empirical Analysis'. *AJOB Empirical Bioethics,* 8(4): 221–233. https://doi.org/10.1080/23294515.2017.1402833.
[141] Kitwood, T. 1997. *Dementia reconsidered: The person comes first.* Buckingham: Open University Press.
[142] Burley, C. V., Casey, A.N., Chenoweth, L., & Brodaty, H. 2021. 'Reconceptualising behavioral and psychological symptoms of dementia: Views of People Living with Dementia and Families/Care Partners'. *Front. Psychiatry*,12:710703. https://doi.org/10.3389/fpsyt.2021.710703.
[143] Spencer, L. 2022. 'Epistemic Injustice in Late-Stage Dementia: A Case for Non-Verbal Testimonial Injustice'. *Social epistemology*, 37(1): 62–79. https://doi.org/10.1080/02691728.2022.2103474.
[144] Carel, H. 2013. 'Ill, but Well: A Phenomenology of Well-Being in Chronic Illness'. In J. E. Bickenbach, F. Felder, & B. Schmitz (Eds.), *Disability and the Good Human Life* (pp. 243–270). chapter, Cambridge: Cambridge University Press.
[145] Chattat et al., 'Promoting Good Living and Social Health in Dementia'.
[146] Quinn, C., Pickett, J. A., Litherland, R., Morris, R. G., Martyr, A., Clare L., & On behalf of the IDEAL Programme Team. 2022. 'Living well with dementia: What is possible and how to promote it.' *International Journal of Geriatric Psychiatry, 37*(1). https://doi.org/10.1002/gps.5627.
[147] Swaffer, K. 2015. 'Dementia and Prescribed Disengagement TM'. *Dementia*, 14(1): 3-6. https://doi.org/10.1177/1471301214548136.
[148] Stokes, G. (2000). *Challenging Behaviour in Dementia: A Person-Centred Approach* (1st ed.). Routledge. https://doi.org/10.4324/9781315168715.
[149] Dupuis, S., Wiersma, E., & Loiselle, L. 2012. 'Pathologizing behavior: Meanings of behaviors in dementia care', *Journal of Aging Studies*, 26, 162–173. https://doi.org/10.1016/j.jaging.2011.12.001
[150] Moyle, W., Venturato, L., Cooke, M. et al. 2016. 'Evaluating the capabilities model of dementia care: a non-randomized controlled trial exploring resident quality of life and care staff attitudes and experiences'. *International psychogeriatrics,* 28(7):1091-1100. https://doi/10.1017/S1041610216000296.
[151] Larkin, M., Craythorne, S., Temple, R., Cottrell, J., Fadashe, C., Lim, M., Lee, C., Bortolotti, L., Broome, M., Tilston, S., McCabe, R. 2025. Involving young people as co-analysts in qualitative mental health research: introducing Dialogical Co-Analysis. Paper presented at the Qualitative Methods in Psychology Conference, British Psychology Society, 9th July 2025, Leeds, UK.
[152] Bergen, C., Bortolotti, L., Temple, R.K., Fadashe, C., Lee, C., Lim, M. and McCabe, R. 2023. 'Implying implausibility and undermining versus accepting peoples' experiences of suicidal ideation and self-harm in Emergency Department psychosocial assessments'. *Front. Psychiatry,* 14:1197512.
[153] Buchanan, M., Blackburn, R. Hayhurst, C. 2022. '1902 Children and adolescent mental health (CAMH) services in the emergency department: UK-wide online survey'. *BMJ Paediatrics Open*, 6.

---

[154] Bergen et al. 2023. 'Implying implausibility and undermining versus accepting peoples' experiences of suicidal ideation and self-harm in Emergency Department psychosocial assessments.' 1.

[155] Bergen, C., Bortolotti, L., Tallent, K., Broome, M., Larkin, M., Temple, R., Fadashe, C., Lee, C., Lim, M. C., & McCabe, R. 2022. 'Communication in youth mental health clinical encounters: Introducing the agential stance'. *Theory & Psychology*, *32*(5), 667-690. https://doi.org/10.1177/09593543221095079.

[156] Tiller, J., Maguire, T., Newman-Taylor, K. 2023. 'Early intervention in psychosis services: A systematic review and narrative synthesis of barriers and facilitators to seeking access'. *Eur Psychiatry*, 6:66(1):e92. https://doi.org/10.1192/j.eurpsy.2023.2465.