

## Special Issue: Intersections and Transformations in Medical Humanities

### Defining and Conceptualising New Paths

**Kristofer Hansson** (Guest Editor), Department of Social Work, Malmö University, Sweden, [kristofer.hansson@mau.se](mailto:kristofer.hansson@mau.se)

**Rachel Irwin** (Guest Editor), Department of Arts and Cultural Sciences, Lund University, Sweden, [rachel.irwin@kultur.lu.se](mailto:rachel.irwin@kultur.lu.se)

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This special issue of *Ethnologia Europaea* explores new paths for our scientific disciplines within the expanding field of medical humanities. Medical humanities have seen a significant expansion in recent years, creating new research foci and leading to collaborations both within and outside of the humanities. As it is a growing academic field, we argue that it is necessary to be part of the medical humanities in defining and conceptualising new paths. The contributions to this special issue demonstrate the ways in which disciplines like European ethnology, folklore studies, social and cultural anthropology can contribute to the expansion, drawing upon ethnographic fieldwork from Croatia, Estonia, Slovenia and Sweden. This special issue opens a space for more collaboration within our fields, as well as with medicine.

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## Exploring Medical Humanities

This special issue of *Ethnologia Europaea* explores new paths within the expanding field of medical humanities in relation to our academic fields of European ethnology, folklore studies, social and cultural anthropology, and adjoining fields.<sup>1</sup> These disciplines, as we argue in this introduction, are important resources for medical humanities, not least to culturally understand the constantly changing medical landscape, as is exemplified in the Covid-19 pandemic. This special issue was initiated before the outbreak, but the work was carried out during the pandemic, and it became obvious how important medical humanities can be to highlight the problem of emerging and re-emerging infectious diseases. Suddenly, most people around the world were forced to deal with the virus both socially and medically. These biosocial processes further exemplified how *culture* is made visible and operationalised in the everyday life of handling a pandemic, or other transformations in the medical landscape. Greeting rituals changed, the importance of a safe home took on a new meaning, and the bodies of the elderly were suddenly considered highly vulnerable and in need of protection. Certainly, it is only with time and distance that researchers will be able to fully reflect on both cultural transformations in the wake of the pandemic and how the pandemic made manifest underlying social structures and fissures (cf. Damsholt 2020; Irwin 2022; Petersson & Hansson 2022). People's experiences of lengthy social isolation, fears and social media campaigns surrounding new vaccines, and diverse policy decisions made by governments in different countries during the Covid-19 pandemic highlight the importance of seriously discussing the importance of developing our methods and theories within medical humanities. Therefore, in this special issue, the knowledge of medical humanities is explored in five articles as a way to refine our analysis tools for the broad questions in our fields. But just as central is understanding how our fields can relate to the medical humanities. We begin with this perspective.

The term “medical humanities” has been used in the United States since the 1960s and in Great Britain since the 1990s (Evans & Alan Greaves 2010). Its more frequent usage in the Swedish context began in the 2010s and has seen a significant expansion since then, creating new research foci and leading to collaborations both within and outside of the humanities, not least within medical education (Bernhardsson & Hansson 2016). The medical humanities are a growing academic field, and we argue that it is necessary for our subject fields to be part of it. The contributions to this special issue demonstrate the ways in which our fields can contribute to the expansion of the medical humanities,

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<sup>1</sup> We use the definition of disciplines that are part of our community, following the international organisation International Society for Ethnology and Folklore (SIEF).

drawing upon, for instance, ethnographic fieldwork from Croatia, Estonia, Slovenia, and Sweden.

The articles in this thematic issue address health and medicine in relation to people's everyday notions and practices, on topics such as the body, cures, and illness narratives. In doing so, the authors explore how approaches from the medical humanities can transform our research questions, theories, and methods. Overall, this special issue further opens a space for more collaboration within the medical humanities, as well as with, for example, medicine, disability studies and public health, broadly defined.

### **Defining and Conceptualising the Medical Humanities**

Our academic fields have not always been a part of the history of medical humanities, particularly within the Nordic context. Rather, they have developed in parallel, yet with many similarities and themes concerning research questions, theories, and methods. That is, while these fields have unique histories, they also have significant overlaps. It is therefore central to understand how the medical humanities have been defined and conceptualised, and how these definitions and conceptualisations can be related to European ethnology, folklore studies, and social and cultural anthropology (cf. Bernhardsson 2014).

Some definitions of the medical humanities are based on the premise that the humanities have a pedagogical role within medical education. As the psychologist, poet, and medical humanities scholar Johanna Shapiro with her colleagues writes, “medical humanities teaching activities share several characteristics” in terms of “methods, concepts, and content [with] one or more of the humanities disciplines to investigate illness, pain, disability, suffering, healing, therapeutic relationships, and other aspects of medicine and health care practice” (Shapiro et al. 2009: 192). These interdisciplinary and collaborative methods, concepts, and content can be used in medical education, including the training for doctors, nurses, and others in paramedical professions.

At the same time, this definition risks creating a scope for topics outside the formal medical education. This is the case if we look at, for example, ethnology and folklore studies in the Nordic countries. By contrast, anthropology and especially medical anthropology have a much longer – albeit still somewhat limited – tradition within medical education.

A similar definition can be found in philosopher H. Martyn Evans' article “Affirming the existential within medicine” where he highlights three manifestations of the medical humanities, namely: as an intellectual enquiry, as part of medical education and finally as “a source of moral and aesthetic influence upon the daily praxis of

organised clinical health care” (Evans 2008: 57). This perspective stresses that medical professions should be trained to see the person behind the patient and to take the patients’ subjectivities seriously. Evans argues that this perspective is central to both diagnosis and therapeutic practice.

Although we also support medical humanities’ pedagogical contributions, we see a risk that meaningful research will fall outside of this narrow definition. That is, there is much research that is of great interest to the medical humanities that cannot be readily included into medical education. This is partly a consequence of the fact that many researchers, like the guest editors for this issue, are not primarily situated in medical schools. For these reasons we argue for a broader definition of medical humanities – a point to which we will return.

Another definition that is related to Evans’ argument, although slightly simplified, is one that sees medical humanities as a subject that is trying to counter the “dehumanization of medicine” (Cole, Carlin & Carson 2015). This definition grasps the existential logic above, but also polarises the differences between medicine and the humanities. It is a categorisation that presents and criticises medicine as a science that objectifies the patient, at the same time as it promotes humanities as better equipped to understand the patient as a person and active subject. This perspective is also found in the critical medicalisation perspectives developed in sociology and anthropology from the 1970s onwards (cf. Zola 1976; Illich 1974; Murano 2018), as well as in disability research (cf. Oliver 1990; Shakespeare 2014) and related fields. While we often take a critical perspective in our own research, we also wish to promote a more welcoming definition that goes beyond critique to invite possibilities for interdisciplinary collaboration with medicine and related fields.

As sociologist Nikolas Rose (2013) argues, we should continue to develop our critical perspective as a possibility to “inject a little more realism” into our research, and at the same time not “be afraid” of the friendship side of building relationships outside the humanities (Rose in interview: Hansson & Lindh 2018: 116). This form of critical friendship can be useful for the medical humanities in that it strives to integrate values and perspectives from both medicine and the humanities, an endeavour that has come to be referred to as an *integrative perspective* (Ekström & Sörlin 2012; Small 2013; Hansson 2019). How can we define medical humanities in relation to a critical friendship with medicine and healthcare? Is it possible to enter these friendships without losing one’s critical perspective? This relates clearly to Shapiro and colleagues’ argument about integration, but instead of only medical education we see possibilities for the humanities to be integrated into medical and care research more broadly (Shapiro et al. 2009).

Through critical friendship we want to argue that our academic fields have a complementary role to play in the medical humanities in comparison with, for example, literary studies and art history. This is an argument that can be supported by Evans' division of medical humanities into three parts (Evans 2007): (1) arts in health, (2) medical education, and (3) critical examination. We have mentioned part two already. Part one – arts in health – falls outside our interest in this special issue because of its focus on aesthetic values. Evans' third area – critical examination – is similar to how research is conducted within our fields. He writes: “The third area is more obviously an academic or theoretical undertaking through and through – namely, the task of attempting better to understand human nature through the lens of a critical examination of technological medicine and its limitations” (Evans 2007: 367). Looking at the contributions to this special issue, we can see that most of the articles relate to this area (although not all focus on “technological medicine”). We advocate a broadening of Evans' definition to include studies that focus on topics regarding public health, disability, care medicine as broadly defined, and not just on clinically-based medical practice. Previous research in our fields also offers examples for a wider scope of critical friendship.

### To Fit In, or Not

We will now turn to ethnology to clarify some of the challenges our academic fields face in relation to the growing field of medical humanities. Although we focus on ethnology here, our perspectives have implications for folklore studies, social and cultural anthropology, and adjoining fields. As a generalisation, there has not been significant interest in creating a “care ethnology” or “medical ethnology” (Öhlander 1999). Rather than a deficit, we see this as an opening for ethnology to be enriched by the medical humanities and vice versa. Indeed, we see this special issue of *Ethnologia Europaea* as an early step in elaborating the many entanglements between medical humanities and adjoining fields.<sup>2</sup>

For example, integrating ethnological perspectives, including cultural analysis, into medical education could provide future medical professionals with the tools to deal with current challenges in medical practice. A few examples of relevant research published in *Ethnologia Europaea* include collective identity through genetic diseases

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<sup>2</sup> Some concrete examples trying to relate ethnology to medical humanities have been done. One example is in the article “Ten case studies in the medical humanities”, arguing for the multidisciplinary possibility with medical humanities (Bernhardsson & Hansson 2016). Another example is “Medical humanities – an arena for challenges and experiments”, where Lundgren suggests “more experimental working methods to create space to maintain complexity in form and content, necessary doubt, ambivalence, incompatibilities and criticism” (Lundgren 2015: 7, our translation).

(Kwaśniewska 2022), violence in close relationships (Kościańska 2020), new medical technologies (Maciejewska-Mroczek 2019), vaccination (Lundgren 2017), and the meaning of silence in residential care homes for the elderly (Ojanen 2016). This type of research has also contributed to the general concept of culture, and how it should be understood and problematised in increasingly diverse and polarised settings.

Yet there are challenges to deepened collaboration between the medical humanities and, for example, ethnology and folklore studies. Our concern is that when trying to define and conceptualise medical humanities, ethnology and adjoining fields are not always represented within medical humanities. To address this challenge, we advocate for ethnology and adjacent fields to not only attend their own conferences and publish in their own journals, but also to actively take the stage in medical humanities fora. This special issue of *Ethnologia Europaea* allows us to pose questions about the core of our research as well as about our theoretical and methodological perspectives. Only then can we begin to discuss our contributions to the medical humanities at large. In this special issue, we highlight three themes from ethnology and related disciplines on which to base this contribution: materiality, cross-case comparison, and folk medicine in rural cultural traditions.

Historically, ethnology and folklore studies focused more on rural, “traditional” societies than they have in the last three decades (Tillhagen 1958; Alver et al. 1980; Rørbye 1982; Alver & Selberg 1987). Older research examined ways in which people experienced illness and cures, including what has often been described as “folk medicine”. This research approached peoples’ experiences as interwoven with both their own (non- or pre-biomedical) health-seeking knowledge and biomedical knowledge about the body (Winroth 2004). It is research that has much in common with the work of medical anthropologist Arthur Kleinman, specifically his interest in illness narratives (Kleinman 1988). These perspectives have been central to the study of medical humanities that wants to counter the “dehumanization of medicine” (Cole, Carlin & Carson 2015) by focusing on the individual as a subject, not simply an object of medical interest. This is a theme that appears in most of the articles in this special issue.

Another important topic in ethnology is the long tradition of interest in materiality. Although illness is very much a bodily experience, there are also many “things” involved in understandings of illness, including places in the physical environment of the “patient” or objects used in curing diseases/illnesses and staying healthy (e.g. Stark 2002, 2006). Most healing processes, regardless of time and place, have consisted of medicines – including so-called traditional medicines and commercially produced pharmaceuticals – as well as other objects that were perceived to be sacred or have

special powers and were used to prevent disease or to improve health. In ethnology, older perspectives on materiality resulted in collecting rural objects for museums, but there was also an interest in writing about their context of use (cf. Bringéus [1970]2003). When we focus on objects in more recent scholarship, our starting point is the material turn in the beginning of the 1990s (cf. Löfgren 1990). Since then, ethnology has been interested in the use of objects and how their form, design and use offer insight into wider social and cultural contexts; that is, the materialisation of illness and cure (cf. Åkesson 2001; Hansson 2007). To take patients' subjectivities seriously – as Evans (2007) advocates – we must also pay attention to materiality. Again, many of the articles in this special issue take up the relationship between various objects – such as antibiotic drugs – and everyday practice regarding health and sickness.

The last theme we want to highlight is present in all of the articles in this special issue. It is an interest in understanding first the broader context and then extracting the specific knowledge that is framed by it, as well as making comparisons between different empirical and theoretical fields. In the medical sciences, the working method is often the reverse. The clinician or researcher focuses on one diagnosis, one disease or one body part or bodily system. The scientific value is to deepen knowledge about the specific. The writers in this issue do the opposite. Starting with a specific example, the researchers seek commonalities with other examples and structures in society. These structures can be other diagnoses, other practices around treatments or even processes outside the health sector; they can also be comparisons between different historical and cultural contexts. Extraction and comparisons are central for medical humanities.

### **Contributions to this Issue**

The contributions to this special issue are varied, but they all speak to the medical humanities' interest in illness, disability, therapeutic relationships, and suffering (Shapiro et al. 2009), while starting from a focus on everyday practices. Through these special issue articles, we argue that the medical humanities together with European ethnology, folklore studies, social and cultural anthropology and adjoining fields can explore the importance of materiality, cross-case comparison, and folk medicine in rural cultural traditions. First up is Uršula Lipovec Čebren's and Juš Škraban's (2022) text "Intercultural Mediation and its Conflicting Allegiances in Slovenia" that examines intercultural mediators in Slovenian healthcare. This is a relatively new profession in Slovenia aimed at assuring equity in access to healthcare, but it also clarifies the complexity that arises when the patients' subjectivities are taken seriously. It is not enough to say that patient subjectivity is central, just as central is an understanding and an attention to power relations. In this article, focus is on the relationships

between healthcare workers, patients, and the intercultural mediators. Through this perspective on relationships, it is possible to pay attention especially to power relations. What Lipovec Čebren and Škraban find is that power relations are pulled in opposite directions: the intercultural mediators are drawn to ally with the healthcare workers on one side, and with patients on the other. This is a good example of how difficult it can be to try to see the patient as a subject in healthcare, to trace out barriers to healthcare for those patients who have migrant backgrounds, and to dissect the logic of a neoliberal healthcare.

The change in healthcare from a more state-funded healthcare system to a more neoliberal and market-oriented system is explored in Tanja Bukovčan's (2022) study from Croatia "Expensive Health: Health-seeking Behaviours in Diversified Medical Markets". In this way it is a study that historically contextualises a transformation that many East European countries have experienced and undergone since the 1990s. Here, patients' voices emerge through in-depth interviews, and they describe their satisfaction with various services and providers within healthcare. This method can also be seen as a way to give the patient a voice and allow the patient to appear as a subject. At the same time, Bukovčan uncovers inequalities in relation to healthcare that problematise the assumption according to which everyone has the opportunity to receive the care they need. Bukovčan finds instead that patients are dependent on parallel payable healthcare alternatives, and that power structures affect health-seeking behaviours on what can be seen as the medical market. The author points to an important lesson here, namely that today's medical pluralism should alert us to focusing more on problems that arise around financing, neoliberalism, inclusion and exclusion.

What is fascinating with medical humanities is that this medical pluralism can also be studied from the perspective of complementary and alternative medicine (CAM), and in this way we can get another view on a similar problem. This is done in Katre Koppel's and Marko Uibu's (2022) article "From Witch-doctoring to Holistic Well-being: Journalistic Representations of Three Influential Estonian CAM Doctors". Through journalistic texts about three influential Estonian CAM doctors, they focus on media representations and how these representations create a polarisation between CAM and biomedicine. This is done in the cultural context of the collapse of the Soviet Union and how Estonia's healthcare has changed rapidly in relation to the international health market since the 1990s. The media landscape has become polarised and CAM doctors need to make choices before they appear in the public sphere about what sort of public figure they wish to be seen as. In this way Koppel and Uibu demonstrate how central it can be for medical humanities to use analysis from other disciplines – such as



media analysis – to study how a society relates to questions concerning health, illness and cure.

In “‘I’m not a jukebox where you push a button and then I sing’: Negotiating Medicine Access in Physician–Patient Encounters” Rui Liu, Talieh Mirsalehi, Margareta Troein and Susanne Lundin (2022) delve into a recurring theme in this issue, namely relationships between care providers and care seekers. Their object of study is Sweden, and like the other researchers in this issue they argue that care services and medicine consumption are undergoing change. They analyse how individual responsibility and consumer choice have become central in a healthcare system transformed by technological changes and a new digital infrastructure. This transformation has led to the emergence of conditions for globalised medical professionals and liberalised pharmaceutical markets. The authors see a risk that physicians are being instrumentalised as only medicine prescribers. But they also focus on the problems with medicines bought and sold outside ordinary regulations, in what they call grey zones. To better understand this complexity, the materiality of medicine itself becomes central. Seeing how medicines have a social life of their own – to use Appadurai’s (1986) phrase – also gives us a better understanding of physician–patient encounters.

Finally, closing this issue, Kristofer Hansson’s and Rachel Irwin’s (2022) article “Controlling Bacteria in a Post-antibiotic Era: Popular Ideas about Bacteria, Antibiotics and the Immune System” addresses people’s experiences with bacteria-as-imagined and the human body. Its aim is to discuss cultural understandings of what it means that society likely is running out of effective antibiotics. This is a societal challenge, and the antibiotic resistance is seen as a harbinger of a so-called post-antibiotic era. The article focuses on how people understand bacteria as both “dangerous” and as “good” and how these perspectives can be used to study the concept of bodily boundaries. Hansson and Irwin also discuss how the concept of antibiotic resistance is used to critique a society that cannot control harmful bacteria. The respondents in their article focus on individual responsibility – self-care – when it comes to controlling dangerous bacteria. Here the concept of a post-antibiotic era can be used in an imaginary way for thinking about future relationships between humans and bacteria – another type of relationship that is vital for medical humanities to study and understand.

Together, we hope that these articles can inspire, challenge, and strengthen the importance of exploring new paths in relation to medical humanities. Our fields have much to add to the medical humanities, to an ever-changing medical landscape and to the global challenges faced by society when it comes to health, illness, and cure.

## Competing Interests

The authors have no competing interests to declare.

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Kristofer Hansson is a lecturer at the Department of Social Work, Malmö University and holds an Associate Professorship in Ethnology. His research focuses on children and young people living with long-term sickness and disability, as well as on medical praxis in healthcare and emerging new biomedical technologies.

([kristofer.hansson@mau.se](mailto:kristofer.hansson@mau.se))

Rachel Irwin is a researcher at the Department of Arts and Cultural Sciences, Lund University. Her research focuses on ethnographic approaches to analysing health policy, particularly at a global level, as well as the history of global health.

([rachel.irwin@kultur.lu.se](mailto:rachel.irwin@kultur.lu.se))

