

THE CENTRE FOR MEDICAL HUMANITIES AND BIOETHICS, LINKÖPING UNIVERSITY

THE IMPORTANCE OF ENCOUNTERS BETWEEN THE MEDICAL HUMANITIES AND BIOETHICS

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Medical humanities and bioethics are engaged in complex questions about the human condition, many of which are both serious and urgent(1). Medical humanities can be understood in a broad sense to include humanities and qualitative social science analyses of experiences of health and illness, medical practices, medical technologies and therapies, with an eye for how these are co-produced with and used in distinct socio-political and historical contexts(2,3). Bioethics can likewise be understood in a broad sense, as the study of moral questions or aspects that arise from within medicine and other life sciences(4,5)⁴.

Further, due to the complexity of the phenomena that are studied, an interdisciplinary approach is often needed. This can enable new research questions, and both broad and in-depth understandings of phenomena of central importance to medicine and healthcare. Such a conviction is foundational in the newly started *Centre for Medical Humanities and Bioethics* at Linköping University, Sweden.

Medical humanities and bioethics

Medical humanities research has developed as a field since the 1970s. It has sometimes been understood to focus on the study of arts and literature within a medical context, or on illness and suffering. Such examinations have contributed a deeper understanding of the human condition, and of the challenges facing every human being living with illness(6). However, as noted above, medical humanities can also be understood in a broader sense. In addition to interdisciplinary medical humanities and social sciences analysis, recent years have seen research collaborations across the arts, the humanities, the social sciences, clinical practices, and biomedical perspectives(7)⁵. Thus the field is heterogenous – and flourishing.

Since its inception in the 1970s, bioethics has studied ethical questions within healthcare, biomedicine and research ethics. Moreover, bioethics can be understood broadly, as including e.g. sociological studies of why certain bioethical questions come to be perceived as central, or studies of how healthcare needs can come to be shaped and created, and this *is* an ethical topic. Whereas some research in bioethics has adopted an applied ethics approach where ethical principles, such as justice and autonomy, have been applied to clinical cases, the field of bioethics also contains other approaches, such as feminist bioethics, phenomenological approaches to bioethics and virtue ethics, to name just a few.

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⁴ Broad conceptions were, for example, suggested in 1970 when Van Rensselaer Potter described bioethics as a “new discipline” that combined human value systems with biological knowledge, and André Hellegers described bioethics as concerned with moral questions evoked in the development of the natural sciences including medicine.

⁵ McLusky does not define the field of medical humanities but propose four core pillars of medical humanities research in order not to define the field too narrowly.

Furthermore, while some bioethics has been distinguished by a purely theoretical discussion with a focus on a clarity of concepts and an aspiration for a persuasive, clear, valid and sound argumentation, in the last decades the empirical turn in bioethics has come to the fore and reshaped the field, at least to a certain extent(8). With the advances in the life sciences, the answers to normative questions such as “what do I ought to do” and “what is right?” are complex. Here, the need for bioethical reflection is of relevance and has great value for clinical practice. In addition, discussions on “reimagining bioethics” are ongoing, inviting discussions between the posthumanities and bioethics in order to broaden reflections such as who counts as a moral subject(9).

We propose that due to the complexity of the phenomena studied within medical humanities and bioethics, there is much to gain from interdisciplinary work not only within each of these fields, but also across them. Medical humanities and bioethics are overlapping fields, and combinations of them can contribute to both fields. This would be the case, for example, in research that asks how social categories such as social class, ethnicity and age affect the medical treatment people receive, and how this influence ethical decision-making. How can experiences from medical practice inform an understanding of ethical principles such as justice? And what epistemic value should be given to such experiences, for the understanding of justice?

Research on the COVID-19 pandemic is one example where the combination of the two fields enables a broader understanding of a phenomenon. The COVID-19 pandemic was a worldwide health challenge that affected people’s lives both directly and indirectly, and the pandemic and the post-pandemic situation continue to raise many ethical, political and societal questions. One of the projects associated with the Centre for Medical Humanities and Bioethics is called “Nurses’ experiences concerning prioritization for health and wellbeing of older nursing home residents during the COVID-19 pandemic in Sweden: a qualitative study”. In the project, nurses working in nursing homes during the pandemic were interviewed about their experiences of prioritisation for the health and the well-being of the residents. The results point to great challenges in caring for elderly individuals who were dying of COVID-19, both on a personal and a professional level, with many narratives giving shape to the experiences of the pandemic. However, the interviews also contributed insights into which ethical questions needed to be discussed. For instance, the experiences of regulations regarding the isolation of people infected with the virus. These regulations, aimed at limiting the spread of the virus, gave rise to ethical questions on the meaning of welfare, justice and equal human rights(10). As a further example, the project “Biomedicine, clinical knowledge, and the humanities in collaboration: A novel epistemology for radically interdisciplinary health research and policy-work on post COVID-19 syndrome’ shows how health problems come to be generated across a wide set of institutional contexts, including political and social contexts. Analyzing in-depth lived experience of fatigue and cognitive decline in post COVID-19 Syndrome, along with clinical assessments, MRI visualization and cytokine profile analysis, the project also attends to how different kinds of vulnerabilities – including economic ones – can co-shape and aggravate a person’s illness. Further, questions of epistemic injustice and of experiences of not being listened to nor believed, tie into ethical concerns for equality in healthcare.

These projects can constitute examples of how medical humanities, with its analysis of, among other things, human experience, contributes perspectives on bioethical discussions, and that a deeper understanding of the human experience can illuminate ethical reflection and decision-making. However, it is a bidirectional critical examination where bioethical research can clarify the ethical problems involved, provide conceptual clarification, and further the discussion on ethical principles. Hence, acceptable solutions to the complex questions about the human condition require an interdisciplinary approach such as encounters between medical humanities and bioethics.

The Centre for Medical Humanities and Bioethics welcomes collaborations

The Centre for Medical Humanities and Bioethics, Linköping University, was formed in 2020 with an aim to promote research, education and collaboration at the intersection of medical humanities and bioethics. We want to advance an international interdisciplinary research culture and welcome dialogues and international collaborations with researchers engaging with and across medical humanities and bioethics.

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