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Health Humanities Lecture Series: Patient Agency

Ylva Söderfeldt (Uppsala University)

'Acting out disease: How Patient Organizations Shaped Modern Medicine'

> April 21, 2022, 4 PM Online via Zoom





Abstract

Contrary to previously established periodizations, patient organizations first emerged in the late 19th century. Throughout the 20th century, they worked towards increased attention to particular illnesses, shared information on disease management, promoted treatments, and developed healthcare resources. In doing so, I propose that they significantly contributed to establishing certain disease concepts and associated practices – and that this deep involvement of patients in medicine in fact facilitated an extended reach of medical power which resonates in contemporary society. Studying patient organizations may help us understand how the idea of diseases as distinct entities was established, how this notion changed the medical landscape and the way we regard ourselves in relation to health and illness. This sheds new light on the role of patients in 20th century medicine and gives crucial insights into whether patient involvement has lived up to the hopes of being a democratizing force in medicine.

Bio

Ylva Söderfeldt is senior lecturer in history of science and ideas at Uppsala University, where she is director of the Centre for Medical Humanities. Her research concerns encounters between experts and the people they are experts on – such as Deaf people and teachers of the deaf, or physicians and patients.