

*Martin O'Malley, Anje Klemm (Eds.)
Cancer Research is a Social Endeavor*



Cancer Research is a Social
Endeavor

An Interdisciplinary Introduction
to Ethics in Cancer Research

*Martin O'Malley,
Antje Klemm (Eds.)*



Herbert Utz Verlag · München

ta ethika

herausgegeben durch

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Band 5

*Umschlababbildung: Detail from a medieval period lintel
in the Wartburg Castle, Quelle: Wikipedia Commons*

*Bibliografische Information der Deutschen Bibliothek:
Die Deutsche Nationalbibliothek verzeichnet diese Publikation in der
Deutschen*

*Nationalbibliografie; detaillierte bibliografische Daten sind im Internet
über <http://dnb.ddb.de> abrufbar.*

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ISBN 978-3-8316-0755-6

Printed in Germany

*Herbert Utz Verlag GmbH, München
089-277791-00 · www.utzverlag.de*

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Knoepffler studied philosophy and theology in Würzburg and Rome (1981-1990) where the Gregorian University awarded him a Licentiate in Theology (1989), in Philosophy (1990), and a Doctorate in Philosophy (1992). He received his habilitation in 1998 and a further Doctorate in Political Science in 2004. He was a Fellow at the Institute for Technology, Theology and Natural Sciences (TTN) from 1996 to 2000 and was appointed Lecturer in Philosophy at the University of Munich in 1998. He then became Deputy Manager at TTN (2000-02) and received an appointment with the Commission for Bioethics with the Bavarian Government in 2001. In 2002, he was a Visiting Professor at Georgetown University, Washington DC. He was then appointed Professor of Applied Ethics at the Friedrich Schiller University of Jena (FSU), where he also leads the center of applied ethics, the EthikZentrum. He is the Vice President of the German Academy for Transplantation Medicine and since 2005 has served as Chair of the Ethic Commission of FSU's Department of Social and Humanistic Studies.

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A graduate of Hamilton College, (BA 1988), he received an MA in Philosophy at St. Louis University (1993), after which he taught for two years in the history and philosophy departments at LeMoyne College, New York. Studying at the Weston Jesuit School of Theology in Cambridge, MA, he received a Masters of Divinity (1998) and a Licentiate in Moral Theology (2008). He received a Doctorate in Theological Ethics from Boston College (2007). Teaching positions include fellowships at Harvard University (1996, 1998) and Boston College (2004, 2005), and Instructor in Theology at Loyola College, Maryland (2004-2006). Research positions include visiting fellowships at The Woodstock Theological Center, Washington DC (1995, 1998), and at the Institut für Gesellschaftspolitik an der Hochschule für Philosophie, Munich (2003, 2005).

Schipanski, Prof. Dr-Ing. habil. Dagmar, President of German Cancer Aid (*Deutsche Krebshilfe e.V.*).

Studied applied physics in Magdeburg from 1962 to 1967 and earned her Engineering Diploma in 1967. She continued studies at the Institute for Semi-Conductors in 1972 at the Academy of Sciences in the Soviet Union in Novosibirsk, graduating in 1976. She received a professorial appointment in 1985, and in 1990 was appointed Professor for Solid State Devices. She was Dean of the TU in Ilmenau between 1990 and 1993, Rector of the TU Ilmenau from 1995 to 1996, and was Thuringian Minister for Science, Research and Art from 1999 to 2004. Since 2004, she has been the President of the Thuringian State Parliament. She was a member of the Science Council of the Federal Republic of Germany from 1992 to 1998 (Chair, 1996-1998), the Berlin-Brandenburg Academy of Science, as well as the UNESCO World Commission for Ethics in Science and Technology. Since 1998, she has been a member of COMEST, the German Academy of Natural Science Researchers, Leopoldina, in Halle, and has served on the International Advisory Board of the University of

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Preface

Martin J. O'Malley

The first Wartburg conference, dealing with human biotechnology, referred to the “social challenge” it posed. In translating the German subtitle *gesellschaftliche Herausforderung* for these papers from the second Wartburg conference, I prefer the phrase “social endeavor”. Endeavor avoids the unintended notions of confrontation contained in the English word “challenge” as well as the notion that the work lies in the future. Endeavor conveys a sense of hope-filled, ongoing collective work, and determined striving for righteous goals. Those are the connotations that are most consistent with the works in this collection of papers on cancer research.

The papers reveal the excitement of potential discovery that presently exists among scientists who study cancer, and they reveal the many obstacles and struggles that stall progress in the prevention and treatment of the many manifestations of this terrible disease. What especially unites the collection is the point that a social commitment is required – that cancer is a risk not only for individuals, but also for communities. For communities to commit themselves to support and direct the research that is necessary to protect themselves, a number of things are necessary. Information about cancer must be available that is comprehensible to non-specialists. This information must present a realistic vision of what is possible and what is most effective for improving the actual lives of citizens. Cancer research requires more than great sums of public and private resources; it needs a structure that benefits from efficient and productive networks of scientists. There is also a requirement that is not so obvious, however. The community must trust that cancer research is guided by ethical ideals that are consistent with their own.

The doctor-patient relationship serves as an important analogy here. Patients, like most members of society, cannot be expected to completely understand their illnesses. Therefore, they must make

decisions based upon a trust that their doctor has their best interests in mind. Because the medical community has earned this trust over decades of faithful service, patients can make prudent decisions about their care based upon the expert advice of doctors. Similarly, society can make prudent decisions in the form of public policies regarding cancer research and treatment, despite the fact that few of us are experts. This is possible, however, only when we share a basic assurance that the research will benefit society and remain within generally accepted moral boundaries. Thus, the papers included in this collection benefit from the expertise of scientists from many different fields of study, but they all essentially function to inform a wide public about the nature of the problem that cancer poses for society, the guidelines that govern research, and the way that research can benefit society.

Just as patients need to engage their doctors regarding medical care, we too need to engage in a rational public discourse regarding cancer research. While we do not need to attain professional levels of expertise, there are several areas where we need to be well informed: We need to understand the basic biological, structural and ethical facets of the problem. We need to know what has been done in the past and what is being done presently. We need to know the questions of justice that are engaged in cancer research and treatment. We need to know the dangers that are posed by research – and also the dangers posed by forestalling research. We need to know how institutions are responding to the demands for research and treatment coordination. And, we need to know about the concrete steps that can be made by individuals, communities, institutions, universities and governments.

Dagmar Schipanski's opening paper builds upon the axiom that research is itself a social process. She played a central role in planning the series of conferences and here she conveys the original conceptions and goals. Having experience in both research and the political process, she sheds light upon the complex matrix of social cooperation necessary for success in dealing with a disease such as cancer. Within scientific research communities, the various disciplines depend upon one another to benefit from the great breath of research tak-

ing place in both the technical and humanistic fields. Structural networks aid this cooperation and foster young scientists as they earn their qualifications and, as peers, enrich the capacity for new insights. She emphasizes the responsibilities that scientists bear to society as a whole, and the communication that is an integral aspect of this responsibility. Cancer treatment benefits from individuals' insights, and leads to the treatment of individuals, but we cannot lose sight of the reality that it is an essentially social endeavor.

Otmar D. Wiestler provides us with a basic sense of the biological processes involved in cancer illness and the great potential benefit of genetic developments. Though we are still at an early state of understanding and thus utilizing genetic understanding for medical treatment, we have some examples that indicate the direction cancer research may take. It is an exciting time, Wiestler assures us, because scientists are beginning to unravel the mysteries of cancer developments in human cells. He sounds a common note by impressing upon us the need to build networks among scientists, but also between scientists and industry because industry is playing an ever more important role in developing medicines.

Paul Kleinhues' paper gathers the data to describe cancer's causes and prevention. Though his paper deals with the science involved, he uses the data from across the world to highlight successes and failures not of science in an isolated sense, but of the role of public policy and its relationship to science. Certainly, there are successes, but the glaring example of the delayed response to asbestos exposure serves as a warning. Kleinhues' outline of national responses to the now well-established dangers of tobacco smoking shows that we are still susceptible to ignoring such warnings. Not only tobacco use, but also lifestyle choices in general can be associated with cancer prevalence. This reinforces the sense that social actions are critically important to consider in reflections upon cancer illness.

Reiner Anselm's paper focuses much more closely upon the ethical issues involved in cancer research. He advocates a more transparent and less restricted use of medical information for the purposes of individual treatment and scientific research, yet he argues that this is

possible only when patients' privacy and wishes are totally protected. Research proceeds on the basis of often unintended consequences, and the availability of medical data is essential to this process, especially as genetic techniques become more refined and commonplace. Once patients can trust that their personal data and therefore privacy are protected and used only according to clear consent agreements, systems can be put into place to provide both better treatment options for particular cases, and better data for further science. This raises the interesting corollary that when people perceive that scientific research is acting independently of social norms, then opposition would likely be raised to the collection and use of personal information. Thus, distinct and understandable limits and boundaries for the use of data are actually more beneficial for scientific progress. With considerations that include personal privacy and the principle of solidarity, Anselm provides a useful set of ethical criteria to guide the way that data can be used for science.

Nikolaus Knoepffler's systematic approach to the ethics of cancer research takes a hard look at the profound inequalities that exist in the world for people in need of cancer treatment. Beginning with a commitment to principles of justice, human dignity, solidarity and universal equality, he sets forth a series of principles to guide cancer research. These principles essentially respect the freedom of particular nations to provide advanced care for their people, but those advances come with responsibilities. Utilizing the basically Kantian insights of John Rawls, Knoepffler insists that health systems must permit individuals' and communities' freedom to secure advanced health care unavailable to the poor, but that inequalities are only tolerated if they produce potential gains for the less fortunate. He pursues this line of argumentation in terms of the principles of subsidiarity and solidarity, and applies his models to the concrete situation in Germany.

Karl G. Blume outlines the structure of comprehensive cancer centers in the United States. The basic idea is to gather the most advanced experts of all aspects of cancer research and treatment together in one center as a way of accelerating progress. The centers are provided with the resources necessary for advanced research and

yet they are focused specifically upon the treatment of patients in associated clinical settings. These centers are enormously expensive, but they have proven to be effective and the model is being replicated in Germany.

Ernst-Ludwig Winnacker's paper fittingly concludes the selection of papers because it offers a view of the future of cancer research and therapy. He offers a sweeping history of cancer research in the 20th century, beginning with the insights of the biologist Boveri, as a way to provide some perspective regarding the potential for future progress. Leading us through basic principles of biology and gene science, Winnacker then tackles the processes by which protein molecules function as important conveyers of information in the cell. He does all this while adhering to the instructions set forth by Schipan-ski in the introduction that the papers must be understandable to lay people. In the case of cancer, he teaches, because these protein molecules play an essential role in the growth of tumors and other manifestations of illness, the ability to control these molecules gives scientists the key to developing cancer medicines. Research centers, building upon advances in genetic science, have opportunities for great progress. Cancer specialists know all of this, of course, but the rest of us require such basic understanding in order to be able to engage in discussions of ethics and public policy.

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Gesamtverzeichnis: www.utzverlag.de