

Health, Technology and Society

Series Editors

Andrew Webster
Department of Sociology
University of York
York, UK

Sally Wyatt
Faculty of Arts and Social Sciences
Maastricht University
Maastricht, Limburg, The Netherlands

Medicine, health care, and the wider social meaning and management of health are undergoing major changes. In part this reflects developments in science and technology, which enable new forms of diagnosis, treatment and delivery of health care. It also reflects changes in the locus of care and the social management of health. Locating technical developments in wider socio-economic and political processes, each book in the series discusses and critiques recent developments in health technologies in specific areas, drawing on a range of analyses provided by the social sciences. Some have a more theoretical focus, some a more applied focus but all draw on recent research by the authors. The series also looks toward the medium term in anticipating the likely configurations of health in advanced industrial society and does so comparatively, through exploring the globalization and internationalization of health.

More information about this series at
<http://www.palgrave.com/gp/series/14875>

Nelly Oudshoorn

Resilient Cyborgs

Living and Dying with Pacemakers
and Defibrillators

palgrave
macmillan

Nelly Oudshoorn
Department of Science, Technology and Policy Studies
University of Twente
Enschede, The Netherlands

Health, Technology and Society
ISBN 978-981-15-2528-5 ISBN 978-981-15-2529-2 (eBook)
<https://doi.org/10.1007/978-981-15-2529-2>

© The Editor(s) (if applicable) and The Author(s), under exclusive licence to Springer Nature Singapore Pte Ltd. 2020

This work is subject to copyright. All rights are solely and exclusively licensed by the Publisher, whether the whole or part of the material is concerned, specifically the rights of translation, reprinting, reuse of illustrations, recitation, broadcasting, reproduction on microfilms or in any other physical way, and transmission or information storage and retrieval, electronic adaptation, computer software, or by similar or dissimilar methodology now known or hereafter developed.

The use of general descriptive names, registered names, trademarks, service marks, etc. in this publication does not imply, even in the absence of a specific statement, that such names are exempt from the relevant protective laws and regulations and therefore free for general use.

The publisher, the authors and the editors are safe to assume that the advice and information in this book are believed to be true and accurate at the date of publication. Neither the publisher nor the authors or the editors give a warranty, expressed or implied, with respect to the material contained herein or for any errors or omissions that may have been made. The publisher remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

Cover illustration: © Monty Rakusen

This Palgrave Macmillan imprint is published by the registered company Springer Nature Singapore Pte Ltd.

The registered company address is: 152 Beach Road, #21-01/04 Gateway East, Singapore 189721, Singapore


For Rob and Bop

Acknowledgements

This book would not have been possible without the cooperation and invaluable experiences of people living with pacemakers and internal defibrillators. My deep gratitude goes to them and their families who welcomed me into their homes for long interviews and conversations. I was really impressed and moved by their openness in telling me how the technologies inside their bodies affected their lives. Although most of them were grateful for having these devices, they also told me about the ambivalences and disappointments of their living with a technologically transformed body. Listening to and learning from them was a real privilege. Although, for privacy reasons, they will remain anonymous in this book, they are the first I want to thank. I hope this book will help to make visible what it takes to live and die with pacemakers and defibrillators. I am also indebted to Wim Smit, one of my former colleagues, who told me about all the work he had to do when he received his first pacemaker. The discussions we had during our coffee breaks made me aware that people living with medical implants are not just passive recipients of technologies that work automatically by themselves, a realization that became the major incentive for writing this book. My deep appreciation goes as well to Bop Dijkstra, who brought me into contact with his patients who have received a pacemaker or defibrillator in the (recent) past. During these interviews, I became very much aware of the vital importance of a general practitioner who provides continuous, personal

care to patients, often for a major part of their lifetimes, and Bop has been a wonderful and very reliable family doctor, as many patients told me.

I am also grateful to those professionally involved in caring for people living with pacemakers and defibrillators, particularly pacemaker technicians/nurses and cardiologists. Without their willingness and cooperation to talk to me and allow me to observe their care practices, this book could not have been written. Because of confidentiality, I thank them here anonymously. Moreover, I would like to thank editor Joshua Pitt and series editors Andrew Webster and Sally Wyatt of *Health Technology and Society* at Palgrave Macmillan, who have been encouraging and helpful editors, and two anonymous referees for their inspiring suggestions that helped me to improve the manuscript. I am also grateful to the reviewers of *Social Studies of Science*, *Science, Technology & Human Values*, and *Sociology of Health & Illness* for their valuable suggestions for revisions of earlier versions of Chaps. 3, 4, and 5. I have also benefited from the discussions and encouragement of my colleagues at the University of Twente and many colleagues and friends in the field of sociology of science and technology in Europe and the US. Throughout my whole academic career, the conferences of the Society of Social Studies of Science have been a warm, intellectual home, and I have relished and benefited from the stimulating discussions of how we can understand the intersections between technology, medicine, care, and everyday life. My deep gratitude goes to Adele Clarke and Jane Summerton for their invaluable friendship, insights, and conversations about what it means to be a feminist STS scholar today. I will always cherish the pleasure and moral support we shared at our pre-conference appointments all over the globe. Special thanks, again, to Gene Moore for his skilful and thorough editing of my English.

Finally, my deepest appreciation and thanks go to Rob Vrakking for his loving, sustained support during the years I worked on this book and throughout my whole academic life. Thank you for the creativity, care, and humour that make living with you into such a rich adventure. And then there was music .

Some of the material included in this book was first published in journal articles. Parts of Chap. 3 appeared in *Social Studies of Science*, vol. 45 (1), 2015, 56–76; an earlier version of Chap. 4 was published in *Science*,

Technology & Human Values 41 (5), 2016, 767–93, and a shorter and earlier version of Chap. 5 was published in *Sociology of Health & Illness* 40 (1), 2018, 171–87. For permission to reproduce photographs and drawings, I would like to thank Josephine Jabara of World Medical Relief, Dr Michaël Laurent, Kees Slagter van de STIN, and Rob Vrakking.

Series Editors' Preface

Medicine, health care, and the wider social meaning and management of health are undergoing major changes. In part, this reflects developments in science and technology, which enable new forms of diagnosis, treatment, and the delivery of health care. It also reflects changes in the locus of care and burden of responsibility for health. Today, genetics, informatics, imaging and integrative technologies, such as nanotechnology, are redefining our understanding of the body, health, and disease; at the same time, health is no longer simply the domain of conventional medicine, nor the clinic. The 'birth of the clinic' heralded the process through which health and illness became increasingly subject to the surveillance of medicine. Although such surveillance is more complex, sophisticated, and precise as seen in the search for 'predictive medicine,' it is also more provisional, uncertain, and risk laden.

At the same time, the social management of health itself is losing its anchorage in collective social relations and shared knowledge and practice, whether at the level of the local community or through state-funded socialized medicine. This individualization of health is both culturally driven and state sponsored, as the promotion of 'self-care' demonstrates. The very technologies that redefine health are also the means through which this individualization can occur—through 'e-health,' diagnostic tests, and the commodification of restorative tissue, such as stem cells, cloned embryos, and so on.

This Series explores these processes within and beyond the conventional domain of 'the clinic' and asks whether they amount to a qualitative shift in the social ordering and value of medicine and health. Locating technical developments in wider socio-economic and political processes, each book discusses and critiques recent developments within health technologies in specific areas, drawing on a range of analyses provided by the social sciences.

The Series has already published more than 20 volumes that have explored many of these issues, drawing on novel, critical, and deeply informed research undertaken by their authors. In doing so, the books have shown how the boundaries between the three core dimensions that underpin the whole Series—health, technology, and society—are changing in fundamental ways.

Other texts in the Series, notably Lynch and Farrington's *Quantified Lives and Vital Data* (2018), have explored personal medical devices both in (such as insulin pumps) and outside (such as biosensor 'wearables') of the body. Nelly Oudshoorn's book takes us—literally—into the heart of the body, providing a careful and detailed analysis of what it is to live with a pacemaker or internal cardioverter defibrillator (ICD). These technologies under the skin are often portrayed as simultaneously magical and mundane: magical because, once implanted, they save and transform lives and mundane because they have quickly become normal, invisible, and automatic. After the initial drama of a heart attack or related problem, the recipients of pacemakers and ICDs seemingly go on to enjoy active lives, undisturbed by this major material intervention. Oudshoorn describes these people as 'wired heart cyborgs' in order to draw attention to the agency and active engagement required to keep the technologies working and the bodies alive. Drawing on recent feminist post-humanist literature, Oudshoorn convincingly deploys the cyborg, not simply as a metaphor but as a conceptual tool to account for the ways in which wired heart cyborgs sense and make sense of their materially transformed bodies. The second part of the book explores the resilience techniques and material resources that may be used by all wired heart cyborgs, independent of their background. In the third part, Oudshoorn draws on intersectional approaches to examine how gender and age matter in the experiences of wired heart cyborgs. The same device can affect the lives of

younger and older women and men in a variety of ways, generating different kinds of anxieties and requiring a range of emotional and medical responses.

Oudshoorn's book provides a rich account of 'wired heart cyborgs.' She also provides conceptual tools to consider other technologies implanted inside the body, such as artificial hips. Much scholarship concerned with the relationships between technology and people focuses on technologies external to the body, more or less under human control and in which the interactions are temporally bounded. Oudshoorn's work is an essential starting point for future scholars who want to explore the agency of people living with implanted technologies that may involve continuous interactions between bodies and technologies that last a lifetime.

York, UK
Maastricht, The Netherlands

Andrew Webster
Sally Wyatt

Contents

Part I	Introduction: Theorizing the Resilience of Hybrid Bodies	1
1	Rematerializing the Cyborg: Understanding the Agency of People Living with Technologies Inside Their Bodies	3
2	On Vulnerable Bodies, Transformative Technologies, and Resilient Cyborgs	37
Part II	Technogeographies of Resilience	61
3	Creating Material Resilient Cyborgs: Sensing and Tuning Agencies of Pacemakers and Defibrillators	63
4	Passive Victims of Faulty Machines? Anticipating and Taming ICD Shocks	93
5	Wired Heart Cyborgs and the Materiality of Everyday Life	117

Part III Resilience and Difference	151
6 ‘How Did You Get that Scar?’ Gender and the Appropriation of Visibly Marked Bodies	153
7 How Age Matters: The Emotional Work of Younger and Older People Living with Defibrillators	189
Part IV How Hybrid Bodies Fall Apart	227
8 ‘Should We Turn Off the Pacemaker?’ Trajectories of Dying and Geographies of Rights and Responsibilities	229
9 The Second Life of Pacemakers: Creating Resilient Implants and Infrastructures for Pacemaker Reuse in the Global South	267
10 Conclusions: Towards a Sociology of Resilient Cyborgs	303
Index	329

About the Author

Nelly Oudshoorn is Professor Emerita of Technology Dynamics and Health Care at the University of Twente, The Netherlands. Her research focuses on the relationships between medical technology, bodies, and everyday life, focusing in particular on the co-construction of technologies and users. She is the author of *Beyond the Natural Body: An Archeology of Sex Hormones* (1994); *The Male Pill: A Biography of a Technology in the Making* (2003); and *Telecare Technologies and the Transformation of Healthcare* (Palgrave Macmillan 2011) and the co-editor of *Bodies of Technology: Women's Involvement with Reproductive Medicine* (2000); *How Users Matter: The Co-construction of Users and Technology* (2003); and *The New Production of Users: Changing involvement strategies and innovation collectives* (2016). Her books have received several awards, including the Rachel Carson Prize from the Society for Social Studies of Science (2005), the Book Prize of the Foundation for the Sociology of Health and Illness of the British Sociological Association (2012), and the Freeman Award of the European Association for the Study of Science and Technology (2016).

List of Figures

Fig. 1.1	Pacemaker (Picture of pacemaker. Images courtesy of Olafpictures via Pixabay. Free download 14 October 2019)	6
Fig. 1.2	The site of a pacemaker in the body (Drawing of an illustration of the site of a pacemaker in the body as included in https://www.cwz.nl/patient/behandelingen/pacemaker/ . Accessed 13 November 2018. Images courtesy of Rob Vrakking)	7
Fig. 3.1	Technician preparing a control visit (Picture taken by the author, courtesy of the heart policlinic at the Amsterdam University Medical Centre (UMC), location VU (Free University), the Netherlands, November 2012)	66
Fig. 3.2	Workstation of the technician with two programmers (Picture taken by the author, courtesy of the heart policlinic at the Amsterdam University Medical Centre (UMC), location VU (Free University), the Netherlands, November 2012)	67
Fig. 5.1	Pictogram to visualize what security personnel should do to ensure a safe passage through security gates at airports (Illustration included in the website of the Stichting ICD Draggers Nederland (STIN). https://www.stin.nl/ Design: J. van Lith. Image courtesy of Kees Slagter (STIN))	123

Fig. 5.2	The thickened site of the body where the pacemaker or ICD has been implanted (https://anatomy.elpaso.ttuhs.edu/clinicalcases/pacemaker/pacemaker.html . Downloaded at February 5, 2019. Images courtesy of Dr Michaël Laurent)	131
Fig. 6.1	Drawing based on a cartoon posted at Wired4life, 5 April 2015. Images courtesy of Rob Vrakking	174
Fig. 9.1	Collection of metal remains of cremated bodies (Picture made by the author, Nederlands Uitvaart Museum Tot Zover)	268
Fig. 9.2	An exploded pacemaker (Picture made by the author, Nederlands Uitvaart Museum Tot Zover)	269
Fig. 9.3	World Medical Relief volunteers selecting donated pacemakers for the refurbishing process (Photo by World Medical Relief. http://www.worldmedicalrelief.org/pacemaker-project)	284