

Chapter 41

Final Thoughts

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We live in a world so uncertain, so chancy, that we seek to fill it with certainty: fundamentalist truth, hard numbers, insurance policies, political correctness, regulatory schemes, IRBs, and tenure. But the truth is, nothing can save you from the loss at the heart of it all, the probability that you will wake, blinking, from a darkness you could not imagine, to a lit world you cannot expect. A fundamentalist politician can have a beloved gay daughter or a 15-year-old pregnant one, Wall Street firms can evaporate, you can lose your job, your house, America can lose wars, lose its cheerful, optimistic way. Nowhere is this uncertainty more terrifying true than in medicine, the tragic world to which bioethics attends. You can get cancer, your child can get cancer, and sickened and afraid, the choices you make just then will bridle or set loose the dark horse that is the future, and it will gallop off into parts unknown.

In this chancy world comes the scientist, and really, it is not her fault that she is so determined. Against the angst of the philosopher, and the desperation of the patients, and the exhaustion of the physician, the scientist must do her work, which is to try to reduce, just a bit, the sense of unknowingness, the mysterious blank undiscovered nature of the world. It is into this world, of chance and loss and uncertainty, that I was invited in early 2003. Teresa Woodruff, a scientist with a big idea, and little more, invited me to think with her about the ethical issues in infertility research, not for women seeking IVF, but for a certain population of women, women facing the mortality and morbidity of cancer who yet yearned to survive and bear children. These women faced a paradox: they had chosen to struggle toward a treatment for cancer, but it bore great risks. First, it might not work or only work for a time. Second, it would likely destroy or diminish their ability to bear children, as we used to say, and non-ironically, naturally. It was one of the first questions a scientist asked me to think about when I arrived at Northwestern and, certainly not tangentially, Woodruff was one of my first colleagues to want a new interdisciplinarity at the core of her research. She wondered: could ovarian tissue be frozen, stored, and then, years later, could the follicles be thawed and coaxed chemically to do what they do normally, which is to self-assemble the human oocyte? Could the egg be fertilized and become implanted in a woman after cancer, to create a pregnancy and a child?

This book is the result of that collegueship and of the official bioethics consultation project, later funded by the NIH in one of nine National Roadmap Grants. As the project grew in scope, I was invited to create a bioethics basic research project, into which I drew

graduate students, undergraduate researchers, and entire undergraduate classes into the labs and the puzzles and the early dawn meetings of the doctors and scientists, the world of activist advocates, patients and families, from whom we came to learn. We invited other scholars from within the university and from other bioethics centers to come think with us, and several of them graciously responded, thus creating a national advisory board. A year later, we were joined by two gifted scholars who have helped create and edit this book.

This book is a collaboration of a new kind and a discussion of a new technology to allow for repair of a new problem. The collaboration is a discussion among research scientists, physicians, philosophers, theologians, legal theorists, social scientists, and historians at Northwestern University refers to emerging interdisciplinary efforts to bridge the fields of oncology and fertility studies in order to develop technologically driven medical solutions to the infertility cancer patients may experience as a result of their illness or its treatment. Techniques that provide women the option of preserving their fertility while deferring the choice of a sperm source until after the crisis moments of cancer diagnosis and treatment are of particular interest to oncofertility researchers. The Oncofertility Consortium takes a multi-pronged approach to expanding the role of fertility preservation as a factor for consideration in patients' treatment plans. These efforts include increasing patient and physician awareness of currently available fertility preservation options, promoting discussion of these options among patients and physicians, and attempting to develop new fertility preservation technologies so that more patients thinking about family planning in the context of a cancer diagnosis will have greater flexibility and options. Oncofertility researchers are studying cryopreservation technologies in order to improve methods for freezing and thawing ovarian tissue, immature ovarian follicles, and mature oocytes. Consortium researchers are also developing in vitro follicle maturation technology, which includes designing an artificial environment that mimics the ovary, in which immature ovarian follicles may grow into mature oocytes. Researchers hope that these oocytes may become an alternative source of eggs for women to use in current assisted reproductive technologies (ART), such as in vitro fertilization (IVF).

New technologies affect the societies in which they are utilized, and the social context of development and implementation also shapes a technology's reception and interpretation by members of society. Even the possibility of pursuing technological advances ought to prompt researchers and society as a whole to reflect upon the ways in which a new technology may change the society into which it is introduced and whether that change is morally valuable, permissible, neutral, or problematic. Oncofertility has the potential to affect societal conceptions of illness, cancer, family, suffering, mortality, and family planning. Consequently, Teresa Woodruff, Director of the Oncofertility Consortium, invited prospective ethical analysis of the fertility preservation techniques under development, in an effort to anticipate and preemptively attend to the ethical dilemmas and concerns that might arise during or due to the consortium's research. These ethical assessments may be informed by a variety of sources, including philosophy, anthropology, law, and psychology.

The work of bioethics, then, is a series of intricate, subtle questions. The book will raise only a selection of the many intense concerns we are raising, largely ones about the moral philosophy and ethics of the work at hand. The book represents a new sort of collaboration, in which bioethics has been a core part of the intellectual arc of the project since its beginning.

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