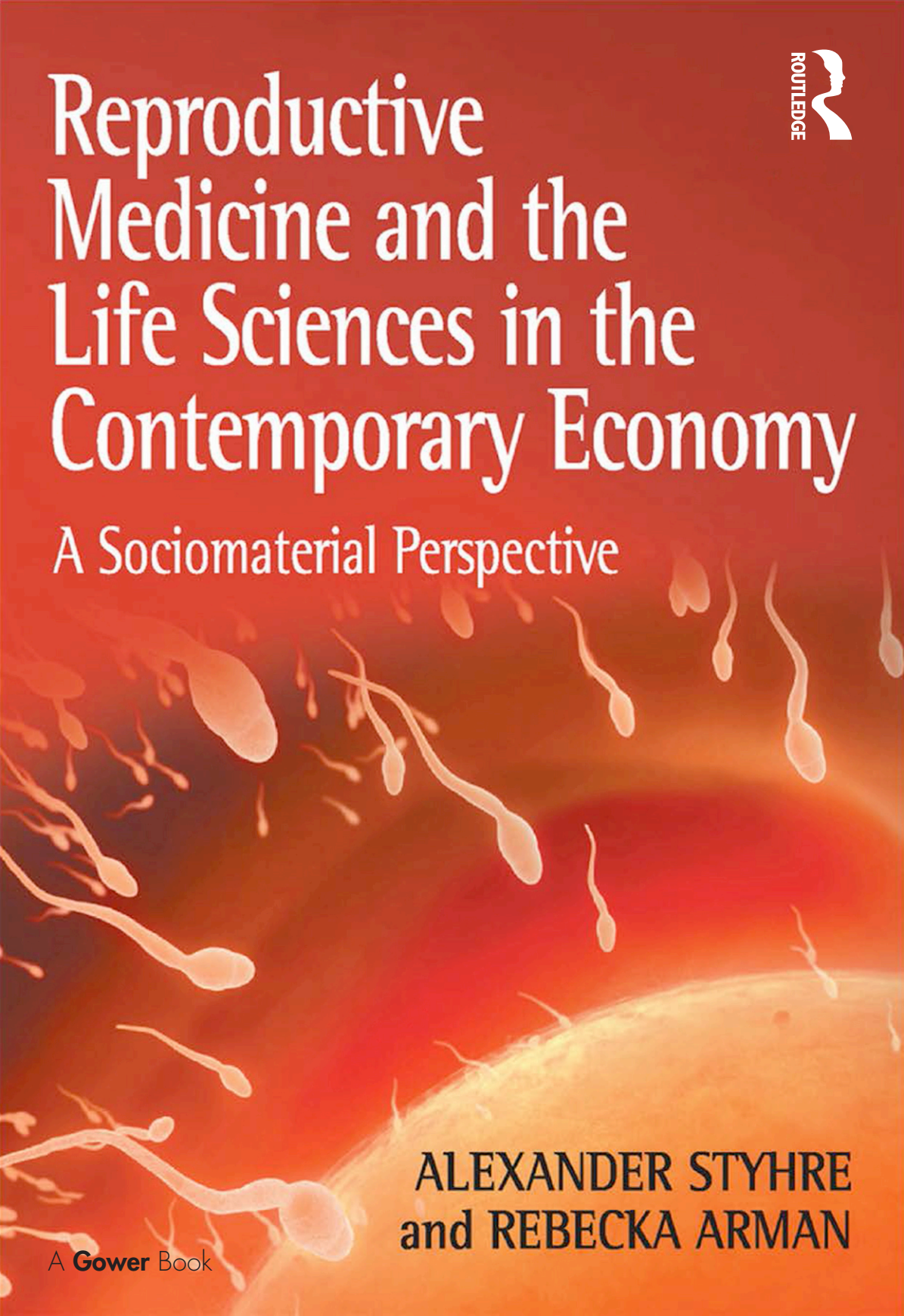
Reproductive Medicine and the Life Sciences in the Contemporary Economy

A Sociomaterial Perspective



ALEXANDER STYHRE
and REBECKA ARMAN

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ALEXANDER STYHRE and REBECKA ARMAN

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Preface

Infertility and human reproduction are undoubtedly a major concern not only for women and men suffering from involuntary childlessness but also for social planners and policy-makers. Like perhaps no other human activity or condition, human reproduction has influenced the culture and organization of human societies. Customs, law, taboos, traditions and economic accumulation are all structured on the basis of how human societies are capable of reproducing themselves.

Over centuries, human reproduction has been subject to systematic study and specialized expertise and especially the women developing a first-hand experience and know-how regarding the delivery of babies in agrarian and rural societies were quite knowledgeable regarding the mysteries of human birth and life. However, medicine did not become an experimental scientific discipline until the first half of the nineteenth century and the development of many sub-disciplines in medicine in the twentieth century has led to a more systematic and scientific understanding of human reproduction. The irony is that the pursuit to understand reproduction was triggered by the threat of overpopulation, still a major concern as natural resources are depleted and global warming may lead to unanticipated changes for human societies, while the very same know-how is today used to fertilize embryos in the laboratory. Science is indeed, as Bruno Latour once suggested, Janus-faced—always being two-sided.

This book sets out to explore and theorize the development and organization of assisted fertilization clinics, the clinical branch of reproductive medicine. It is written from an organization theory perspective and while one of us (Rebecka) has formal training and experience from medicine and healthcare work, we do not intend to primarily examine the medical aspects of assisted fertilization practice. On the other hand, it would be meaningless to study the clinics and the everyday work without saying at least something about reproductive

medicine, and consequently we try our best to explain the various practices involved in the work.

When searching for literature and studies of assisted fertilization clinics and its practices, we have learned that there is little within the social science literature to draw on. While much is written in general about assisted fertilization and especially from certain favoured theoretical perspectives (e.g. feminist theory), there is still a shortage of ethnographic studies of the field. Also in the field of organization studies there is almost nothing written about this domain of the life sciences.[1] This is perhaps somewhat surprising given that the field of reproductive medicine and assisted fertilization clinics contain many of the issues that organization theorists concern themselves with: innovation, entrepreneurship, the role of law, regulations and institutions, professionalism, and so forth.

Since this book is one of the first works produced addressing assisted fertilization therapies and clinics in organization studies, the theoretical framework developed and used is multidisciplinary and includes contributions from many different social science and humanities disciplines. The aim of the book is still, as is being argued in the final chapter, to make an organization theory contribution to the study of the commercialization and institutionalization of the life sciences. Without making too bold a statement regarding our possible contribution, we think this is one early effort to understand the expertise, know-how and entrepreneurial foresight needed to advance assisted fertilization to the position it has entrenched today as a safe, credible and very much appreciated contribution to society, especially for women and men suffering from infertility.

The long-standing call for making business school research more "socially relevant" (here we could reference a long series of worried editorials and "discussion papers" published over the last few years, but we will skip that routine this time—readers craving examples can check the first section of the last chapter) is perhaps best handled by studying things that matter to people. Reproduction of course does. We thus believe that assisted fertilization clinics are worthy of more scholarly attention outside its traditional disciplines (e.g. gender theory and science and technology studies) and hope that we are capable of setting an example or at least provide some inspiration for further research with this research volume.

1 Brewis and Warren (2001) discuss pregnancy from an organization theory perspective but more from a conceptual angle than an empirical study.

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We would like to thank all the representatives of the field of reproductive medicine and assisted fertilization for participating in the study. Alexander would like to thank all his colleagues in the organization and management section at the School of Business, Economics and Law, University of Gothenburg, for commenting on various texts-in-the-making over the last few years. In addition, seminar participants at University of Innsbruck and at the Norwegian Business School in Bergen where research work appearing in this volume was presented should be recognized for their helpful comments and questions. Rebecka would like to thank Professor Gideon Kunda and the Visiting Professor Program Post-doc group at the School of Business, Economics and Law for comments and a fruitful exchange of ideas.

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PART I

Theoretical Perspectives

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Introduction: The Predicament of Childlessness and the Baby Business

Experiences from Assisted Fertilization

> *Firsthand thinkers mediate upon things; the others on problems. We must live face to face with being, and not with the mind.*
>
> *E.M. Cioran (1998: 43)*

Reproductive medicine and assisted fertilization are dealing with human reproduction, the elementary processes of life, and a central concern in any culture or human society (Ginsburg and Rapp, 1991). Indeed, we need to live our lives in the immediate connection to things. In Platonist thinking and in the Christian tradition, the material, everyday life world is downplayed and instead the "higher" and "eternal" issues beyond this crude and unfulfilled world are acquiring prestige and status.[1] However, there is nothing that makes human beings more acutely aware of their own material and biological existence than the loss of health (Frank, 1995). Instantly, the world around us crumbles as our human bodies cease to function as anticipated and we easily surrender to faith and folk belief as we hope to be able to restore ourselves. When the body hurts and aches, the higher values and intellectual discourse quickly loses its relevance for us. Rather than starting a research monograph on assisted fertilization with the theoretical domain, we will thus first encounter a few persons, couples of women and men, with first-hand experience of lending themselves to the practices of assisted fertilization.

1 In Plato's ideal state, presented in *The Republic,* the world of economy and commerce supports the world of politics and legislation which in turn supports the world of philosophers, the literati and intellectuals. Society is constituted as a hierarchical arrangement based on strict division of labor and responsibilities. *Skholē*, the freedom from work, is for Plato the highest degree of prestige, enabling reflection and what Martin Heidegger speaks of as *philosophieren*.

Rather than outlining a sophisticated conceptual framework or pointing at statistics indicating the relevance and scope of assisted fertilization, we will now enter this inquiry through a few life stories. These life stories, being told by two couples, one couple with positive experience from assisted fertilization inasmuch as they eventually became parents and today have a son, and one couple with a more negative experience filled with exhausting years of hope and despair ending with the insight that they would not be able to become parents, are by no means representative of anything else but their own experiences. Nevertheless, these stories being told may help us enter a more complex narrative including a variety of heterogeneous resources and conditions that taken together constitute what is called assisted fertilization. If nothing else, these vignettes from the world of assisted fertilization may help us think of these advanced technoscientific procedures and field not as an abstract system of interrelated and in many ways obscure and esoteric activities but as series of encounters and activities that in their own ways constitute assisted fertilization as what it is, as an encounter with technoscientific expertise that in many ways is impressive in what it is capable of accomplishing or at times even intimidating but that nevertheless is dealing with human reproductive materials under highly specific conditions. Hopefully assisted fertilization, its accomplishments and limitations, may become intelligible in this volume.

The first couple suffered from the female's illness, endometriosis, a medical condition reducing fertility. When deciding to seek assisted fertilization help, they were not naïve regarding their chances of becoming parents: "They [clinic staff] did not make any promises given [the woman's] diagnosis. They have never been able to say very much besides general statements … So I thought they conveyed adequate information and there were no false expectations but they were rather straightforward" (Male IVF patient, Couple 1). The initial hope that the assisted fertilization therapy would be able to help them become parents soon led to disappointment and despair. The couple endured a four-year period where they returned to the clinic for repeated treatment cycles after failing to get pregnant. After undergoing a few failed treatment cycles the woman learned to anticipate and feel the reactions and shivering of her body:

> *In the beginning, I was full of hopes and really believed in this, analyzing every single little feeling, that "this might be something this time," but then you were devastated when it didn't work. After a few times, I tried to convince myself that this time I mustn't become sad if it fails but nevertheless you were totally broken just the same. Every single time! Those days when you realized that*

> *this won't work this time either, you were broken down … but then through the denial or repression that I used [I could continue]. (Female IVF patient, Couple 1)*

She continues:

> *Either you start to bleed or if time passes you can take a [pregnancy] test at home. But I have been able to sense it every single time. I get this ache … I get certain symptoms, like an ache in my thighs and being heavy in the legs and all sorts of things, so I have been a hundred percent sure that this is it! A few days before the actual event [the miscarriage]. (Female IVF patient, Couple 1)*

Every single miscarriage was a painful, emotional event wherein the couple suffered a wordless sense of disappointment regardless of their understanding of the woman's medical condition. To cope with the situation in an orderly and somewhat emotionally detached manner was therefore of great importance. When they asked the clinicians why there was such limited progress, they were not able to get any clarifying answers:

> *After a few treatment cycles, we were starting to … become concerned regarding the lack of progress, then I asked a few questions to the doctors … then they were telling us that "there are better chances with the fresh trials rather than with the frozen [embryos] and that the success rate was higher in such cases" … When we have done like, six, seven, eight embryos, they were starting to tell us that they were concerned regarding the lack of progress. (Female IVF patient, Couple 1)*

Rather than telling their families and friends, the couple had decided not to tell anyone, potentially making the ordeal an even more demanding experience as they had to maintain a secret everyday life. The reason for this secrecy was to avoid further disappointment among, for example, their parents: "We didn't want to carry their [parents'] expectations as well … Of course we knew … and they have given us a few hints as well … that my parents were wondering why there were no grandchildren coming," the woman argued.

As the years passed, the couple almost lost count of how many cycles they had undergone. After the second campaign of treatment, around the tenth cycle, they both lost their faith in fulfilling their dreams of parenthood but continued until the fifteenth cycle, just to be sure that they "had done everything they possibly could": "It felt definite after the second round of

treatments. The third round was just a mere formality, more than a real, serious attempt" (Male IVF patient, Couple 1). He continued: "We have done what we could and we cannot go any further. Now we have to live with that. There's nothing we could have done differently. And that feels good" (Male IVF patient, Couple 1). Even though the man claimed that he feels good about having the energy and determination to be able to do all that was asked from them, there is still a strong sense of disappointment and disillusion: "I suppose we were prepared, more or less, but it felt like … well, we had tried for many years … consuming so much energy both from us and from work … ruining the body, and things felt … well, unfulfilled" (Female IVF patient, Couple 1).

Needless to say, for the couple these were not happy years, years filled with joy and laughter. Instead, the period was exhausting as everyday life had to be maintained at the same time as therapy continued:

> *I don't think I had any regular everyday life during these years. Things have been exhausting and both of us have been tired because of all the hopes and the sadness you have to live with when things came out this way. The medication hasn't been particularly mild … You get emotionally labile … It is tough. (Female IVF patient, Couple 1)*

There are few possibilities for identifying any positive experiences from these years in the clinic. At least, being able to keep their relationship despite the pressure was regarded as a joint accomplishment:

> *The best part is that we're still in a relationship, that it did last … It is quite demanding to endure this kind of situation. First, the grief in itself in not being able to become parents when you want to and then the sense of guilt on my part, being the source of all this. It is not a happy situation. (Female IVF patient, Couple 1)*

When being asked about their view of the work in the clinic, the couple lacked a sense of an integrated view of their case, moving back and forth between the woman's endometriosis specialist and the clinic: "There is no integrated perspective. But we have been very well treated by all midwives. If it's been one professional category that has been nice throughout, it is them—every single one of them!" (Female IVF patient, Couple 1).

Despite their inability to become parents, they believe the Swedish healthcare policy is quite "generous" in letting them undergo no less than 15 treatment cycles:

> *Female IVF patient, Couple 1: Today, I'd say it is quite generous, actually.*
>
> *Male IVF patient, Couple 1: Yes, I think so too … We have been given like fourteen or fifteen treatment cycles and that is amazing when you think about it. You need to say that it is generous.*

Adoption is not necessarily the solution for the couple as they regard that as an "entirely different thing" than having a child of one's own. "That would be another issue to handle and think through if we would be willing to do that," the woman responded. "It is like night and day. There are like eleven new issues popping up in comparison to having children of one's own … So it's very different," the man added. Adoption is at best a form of substitute to giving birth to one's own biological children. In summary, the couple was pleased they had the stamina and energy to follow their path chosen to its very end but besides that the assisted fertilization therapy was, despite limited expectation, an exhausting and ultimately disheartening experience. Also the time spent in the clinic was complicated to predict: "When we started, we did not know how long time it would take … We did not believe it would last for four years," the man reflected.

The second couple could tell a less heartbreaking story inasmuch as they managed to become parents, but their story also includes failures and despair. As with the first couple, the female is suffering from a medical condition but in contrast to the first couple, the second couple started to consider adoption but they were turned down because of the man's age: "We were quite confused [after being turned down by the adoption bureau] and we felt like 'this is the end of the story,'" the woman said. Turning to the assisted fertilization clinic, the first step was the hormone therapy to enhance ovulation. The woman said she had a "terrible anxiety" regarding the therapy after hearing "horror stories" regarding the uses of hormones: "January was a black month, not because I was possibly becoming pregnant but because I feared becoming ill … You always hear these horror stories about what happens during the hormone therapy" (Female IVF patient, Couple 2). She continued: "I called them [the clinic] totally messed up and told them about my concerns. I wanted them to say something like 'one in three million suffer from such side-effects,' but instead they told me that 'this is your decision.' Well, they told me so, but I was so frustrated

and even more stressed by not getting any advice or counseling" (Female IVF patient, Couple 2).

When telling her husband about her concerns, he said that he was willing to drop the entire idea of assisted fertilization if the cost would be a constant ongoing anxiety for his wife. The woman declined all such ideas:

> *We were almost beginning to fight, because he said that "well, we don't need to do this if you are suffering this much," but I said no! (Female IVF patient, Couple 2)*

> *I just wanted to emphasize that this was not a life-or-death matter for us, that we needed to have a child regardless of the costs … In that case, we could terminate the process. (Male IVF patient, Couple 2)*

After some time, the woman managed to handle her fears and experienced relatively little side effects. The next unpleasant experience was the egg retrieval, perhaps the single most unnerving experience:

> *And then they retrieved the eggs and that was probably the most horrible thing in the entire process. It was no walk in the park, I can tell you. You're like lying down in this gynecology chair and you get loads of morphine but that is the only good part about it … I had to ask them all the time, "more morphine, please" because it was really painful. (Female IVF patient, Couple 2)*

Using a needle to enter the ovaries through the vagina, the egg retrieval is a most advanced procedure that safely retrieves a number of oocytes, unfertilized egg cells, to be fertilized in the laboratory. After 36 hours, the couple returned to the clinic for the embryo transfer. After the transfer, a short period of waiting for results led to a disastrous outcome:

> *Female IVF patient, Couple 2: And then on the Sunday we returned to make the first transfer. They had six eggs all being fertilized. Four of them were accepted because they need to be perfectly divided and everything … Then came the two most dreadful weeks. Even before I had made the pregnancy test, I woke up this morning bleeding … it was terrible … I just cried … I was "the world's least successful woman" … Everything was totally black and I felt this is not going to end as we planned for.*

> *Researcher: So it felt like a personal failure?*

> *Female IVF patient, Couple 2: Yes, it was very dramatic. I think I cried for three straight hours.*

The woman strongly felt the miscarriage was a personal failure and responded very emotionally. Her husband, having friends successfully undergoing the treatment and becoming parents, knew that it is not very common to succeed in the first attempt and kept calm. His wife was at times annoyed by this attitude: "At times, I thought he was just so insensitive when telling me [to relax and calm down] but at the same time it felt very good to have someone standing firmly on the ground" (Female IVF patient, Couple 2). Unlike the first couple, the second couple decided to share their predicament with friends and families so they could get their support: "Some people tell no one but I felt, and [the husband] did the same, that … unless I tell anyone, there is no one to help me when I am sad because things may go terribly wrong. That's me, anyway, rather speaking freely so people are informed" (Female IVF patient, Couple 2).

The couple continued the therapy, using one of the embryos in the freezer, and this time the outcome was different. The woman could account for the details when she realized she was pregnant:

> *It was ten to five in the morning when I did the pregnancy test. I was sitting there, half asleep and just all of a sudden, What!? I just bounced up to the second floor where [the husband] was sleeping, telling him "I'm pregnant." And he's like "Great!" I was lying there, eyes wide open, not a bit tired and waiting for the morning to come. When he woke up I told him again, and he said like "Yes, I heard you the first time. Brilliant!" (Female IVF patient, Couple 2)*

This time, the pregnancy ended with the birth of a healthy son in 2009 and today they live a family life similar to that of millions of other families. Especially the woman expressed her fascination over the fact that the once frozen embryo could be transformed to a living baby: "He [the son] was frozen for like two months. Only that is a miracle! It is so wonderful … I am so fascinated by the fact that the embryo has been in the freezer" (Female IVF patient, Couple 2). The other side of coin is that the embryos still in the freezer in the clinic become a concern, an issue to be eventually dealt with:

> *It [the embryos] can stay in the freezer until 2013, a five year period I believe … If we have not made the second transfer, I think it will be hard to have it destroyed since we know what came out of it … But we'll cope with that in due time … We have decided since long that there will be no more [children]. But*

> *it is haunting us, being there in the freezer … That is the case. (Female IVF patient, Couple 2)*

For instance, during the therapy, the couple were asked if they would agree to donate embryos to stem cell research after their embryos had passed their five years in the freezer—the maximum period for embryo storage according to Swedish law—but, after long discussions, they decided that they did not want to donate their embryos. "We were not willing to donate to stem cell research … but we agreed on something else—but not stem cell research. We didn't want that … We were talking quite a bit about it. It felt like some kind of violation of the personal integrity" (Female IVF patient, Couple 2). While embryos are destroyed after five years, the couple felt there were too close connections between the embryos in the freezer and their son, leading to their joint decision.

When being asked about their experience from the assisted fertilization clinics, the second couple, just like the first couple, did not develop any personal contacts in the clinics but were rather treated as patients in an anonymous healthcare process: "What is missing are the personal contacts. I know the system is based on standardization … [But] in assisted fertilization it is so important to have this kind of continuity. And I cannot say we saw much of that," the man argued. "It is a 'disruptive relationship' [with the clinic staff] you may say," the woman added. Despite this sense of lack of personal relations in the healthcare work, the outcome from the therapy was what was hoped for, a child to care for.

The experiences of these two couples may or may not be typical or representative of how assisted fertilization therapies work or unfold. Some become parents, but many don't; hopes and expectations accompany the physical ordeals or even sufferings of the female patient; limited theoretical and practical understanding of the human reproductive processes and organs prevents credible explanations for both failures and successful pregnancies; ethical and practical issues needs to be addressed *en route*. The assisted fertilization clinic is a site where human hopes and "biological instincts" (used here for the lack of a better term) are bound up with advanced technoscientific apparatuses and procedures. The assisted fertilization clinics are no "wonder factories" managing to accomplish anything but every time they succeed in producing new babies it is regarded as the wonder of life by the lucky parents. Assisted fertilization clinics are both deeply seated in human needs and aspirations at the same time as they are advanced technological sites. This venturing into the secrets of human reproduction is a fascinating endeavor,

and numerous couples and single women have been able to take advantage of this clinical expertise. At the same time, failure and despair accompany the clinical work, leaving many couples, like the first couple above, in a situation where they gradually reach the painful insight that even the state-of-the-art technosciences may not be able to overcome the hurdles put up by nature.

In the contemporary era, childlessness is not only an unfortunate predicament beyond human influence but is also transformed into a "medical condition" that may be corrected and modified in clinical procedures. Reproductive medicine gives hope to sub-fertile couples but also leads to a variety of social concerns and ethical issues to be handled and debated. In addition, assisted fertilization work is organized on basis of certain principles and rationales that have been subject to relatively little scholarly attention. In the following, this technoscientific domain of work and economizing will be explored in greater detail.

The Baby Business

In 1932, Aldous Huxley published his dystopian vision of the future world, the emblematic novel *Brave New World*. Unlike George Orwell's equally famous *1984*, Huxley's image of the future is not a totalitarian society in the tradition of Nazi Germany or Stalin Soviet Union wherein people are oppressed on basis of an intricate system of surveillance, control and penal practices. For Orwell, the future in the 1980s would merely be a continuation and amplification of what was already observable in the 1930s in fascist and communist countries in Europe.

Huxley was more visionary. In his brave new world, people are no longer oppressed in the traditional sense of the term because they do not experience any oppression. Instead, Huxley portrays a society wherein science and technology have acquired a hegemonic position and where human happiness is accomplished on the basis of pharmaceutical substances, a widely used drug called soma. Perhaps the most spectacular accomplishment of this future society is that rather than resting on "natural" human reproduction, all reproduction is organized as an industrial process wherein five distinct classes of human beings are created, each equipped with the adequate intelligence for the role they serve in society. The Alpha humans are highly intelligent and are developed to conduct qualified and intellectually demanding work while, on the lower end, the feckless Epsilon humans are designed to conduct menial

tasks and have little ambition besides doing what is expected from them. Huxley's future society is thus a far-driven class society wherein there is no need for social selection or social migration because such concerns are already resolved in the industrial process of human reproduction. While *1984* offers a few possibilities for resistance and hope, *Brave New World* is in many ways a more chilling scenario for the future.

Among the key terms that Huxley proposed is the concept "test-tube babies," a concept that in many ways effectively exploits the common-sense binary separations between nature and artifice, life and inert matter, natural reproduction through intimacy and intercourse and cold, disembodied laboratory procedures. Huxley's term test-tube baby has been consistently used in the discourse on assisted fertilization. No matter how many stories of despairing parents facing fertility problems but successfully becoming parents through the help of assisted fertilization procedures, Huxley's *Brave New World* still haunts the domain of reproductive medicine and assisted fertilization. In fact, the term test-tube baby is one of the first terms that one tends to associate with assisted fertilization. Also the very term in vitro fertilization (IVF), a common term to denote assisted fertilization, means literally "in the test-tube fertilization."

While other areas of advanced medical practice, ranging from molecular biology to organ transplantation, are commonly admired for their capacity to intervene in the human body and to restore functions and to eliminate injured or poorly functioning organs and tissues, reproductive medicine and assisted fertilization is not only combating scientific, technical and financial difficulties but also something potentially much worse—common-sense thinking. Human reproduction and parenthood are undoubtedly deep-seated emotional, social and cultural events in any society (Ginsburg and Rapp, 1991). Virtually any human society appears to have instituted rituals, ceremonies, taboos and institutions pertaining to the domain of human reproduction. In the Greco-Roman or Judeo-Christian cultural tradition dominating in Europe, the marriage between a man and a woman is instituted as the only legitimate social arrangement wherein human reproduction is socially sanctioned. Only recently has the legislation been liberalized, making lesbian couples, for example, eligible for the assisted fertilization therapies. For centuries, out-of-wedlock births have been a source of social scandals and controversies, and many women have been ostracized if they have been unfortunate to become pregnant prior to their marriage. To avoid such social stigma, at times lasting