Chapter 28

Perspectives on Oncofertility from Demography and Economics

Rosalind Berkowitz King
R.B. King (B) Demographic and Behavioral Sciences Branch, Eunice Kennedy Shriver National Institute of Child Health and Human Development, Bethesda, MD, USA e-mail: rozking@mail.nih.gov

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Introduction

The science of demography focuses on the drivers of population dynamics: fertility, mortality, and migration. Demography is inherently interdisciplinary and draws on theory from a range of social sciences, including sociology, economics, and anthropology. The demographers' approach to fertility research at a given time is grounded in the contemporaneous fertility trends and fertility-related technology at the societal and individual levels. For example, the founding of demography at the turn of the twentieth century coincided with declining fertility levels among the most affluent and educated families, a bimodal pattern of high fertility or childlessness among families at the lower end of the socioeconomic spectrum, and Margaret Sanger's public health efforts to support the availability of contraception. Thus, demography was originally deeply concerned with fertility control as defined by the ability to stop having children after reaching the desired family size. As US fertility patterns settled into nearly universal parenthood with most families having two to four children in the 1950s, demographers turned their attention to "uncontrolled" fertility in the developing countries of Asia and Africa. The most consuming fertility issues of the 1970s reflected the technological development of the contraceptive pill and the social development of increasingly non-legitimated teen births.

In the twenty-first century, much about fertility has changed. Some lines of differentiation in fertility patterns among Americans have lost their influence, as seen in the general convergence in completed family size across religious backgrounds. Many more methods of contraception are available and access to knowledge of these technologies has generated fertility declines for families across the world except for parts of Africa. But fertility-related technologies for creating and maintaining pregnancies have only become highly developed in recent decades, and their use has not yet become widespread enough to make an impact at the societal level (for a first analysis, see the work of Hoorens and colleagues [1]). Demographers today spend less scientific effort on fertility control as traditionally explored, but they have not yet felt a strong impetus to research aspects of fertility control such as the power to create children around barriers. The science of contraception is well documented and the science of infertility is scant.

Nevertheless, the sociological, economical, and anthropological concepts on which demographers have drawn to explain fertility patterns and contraceptive behavior can be

usefully applied to infertility. Here, I begin to lay out how demographic theory and concepts from economics can shed light on questions of interest to researchers in the emerging field of oncofertility, the preservation of biological fertility in cancer patients.

Why Have Children in the Twenty-First Century?

Before considering oncofertility specifically, we should consider more generally why individuals and families today desire to have children. Historically, people did not have a great deal of choice about having children. Sex and reproduction are basic biological functions, and the former, a popular activity, generally led to the latter [2]. The social construction of specific family forms and rules for who could join with whom to create a family provided some control over the frequency of sexual partnering but not over its outcome. Societies developed institutions such as craft guilds and nunneries and informal systems such as fostering to provide outlets for parents to dispose of children for whom they were either unable or unwilling to care.

When contraception becomes available and socially accepted, fertility declines and the decline is often steep. Current total fertility rates in the most developed societies range from a low of 1.2 in Poland to 2.0 in the United States. However, childlessness is still a minority status, reaching a recent high of 20% among women ages 40–44 in 2006 [3]. People apparently want children, just not very many of them.

Since mortality is inevitable, all social entities – individuals, families, communities, and societies – must reproduce in order to continue their existence into the future. The two main goals of individuals and society are production and reproduction: to make and consume material goods and to make members who will continue those processes and actions. But the time and resources needed for production and reproduction are finite, and thus individuals and societies need to make choices about how to allocate scarce capital. Economics is the social science that studies these decision-making processes.

The first economic theories of fertility came from classical and neo-classical economics. Classical economics viewed individuals as rational actors whose decisions were grounded in reason. Neoclassical models such as Becker's "New Home Economics" allowed for motives such as altruism but incorporated them logically into the utility maximization model [4]. A rapidly developing subfield within contemporary economics is behavioral economics, which blends insights into human behavior from psychology into economic models of decision-making. Behavioral economics allows that the decision maker may act from a position completely driven by emotion or non-rational motives. (Economists agree that rationality and emotions are both cognitive processes; whether or not they are exclusive of each other is a matter of debate.)

The most important aspect of economics for bioethicists is that economics is not concerned with morality. Classical economics aims to explain supply and demand for goods and services as determined by the behavior of rational actors with "perfect" information in free markets. Values are encompassed in the preferences of rational actors; preferences are stable and generally relegated to the error term in statistical equations.

Neoclassical and behavioral economics allow for more complicated thought processes but still refrain from discussions of “right” and “wrong.” Economists study topics such as discrimination and organ selling, but they argue only the circumstances and outcomes without making statements about whether such activities should or should not be pursued.

In the sections that follow, I list several concerns presented by interdisciplinary scholars at the annual humanities and social sciences meeting of the Oncofertility Consortium. Under each question, I provide an economic concept and suggest how it could be usefully applied to the existing discussion. These suggestions are admittedly sketchy in nature and I leave a more full development of each to future work by interdisciplinary researchers. I encourage oncofertility investigators to utilize the reference list presented here for a more comprehensive understanding.

How Can Economic and Social Demography Help Us to Understand Oncofertility?

Why Would Patients Pursue Fertility Preservation Rather than Adoption?

Risk, Information, and Uncertainty Reduction

On a purely theoretical basis, the rational actor has perfect information about the various courses of action available to her to pursue. In practice, information is always imperfect, and the accompanying uncertainty generates perceptions of risk for the actor. The transition to parenthood is particularly challenging because it most often requires making a permanent commitment to an individual whom one has never met and thus about whom one has little to no information. In the case of biogenetic childbearing, actors rely on their knowledge of themselves, their partner, and their own families of origin to predict the characteristics of the potential child. The motive of uncertainty reduction is one reason that biogenetic childbearing is preferred to the use of donor gametes, gestational carriers, and adoption. In each of those cases, the parents will have less information about and control over genetically transmitted traits, the intra-uterine environment, or both. While adoptive parents may have the opportunity to meet the child before committing to parenthood, this advantage of current knowledge is undercut by lack of knowledge about the child’s life experiences to that point; Americans place a great emphasis on genetics and early rearing and view taking responsibility for a child for whom they have not controlled those factors as risky [5].

For oncofertility patients, a significant piece of information about their genetic heritage is the likelihood of a predisposition to cancer. In the case of a child with a genetic condition for which testing can provide information about the likelihood of the same disease appearing in genetically related siblings, a physician’s duty to warn requires him or her to alert the parents [6]. But in the private context of biogenetic parenthood, the use of this kind of information with regard to decision-making about the child’s reproductive future is left to the family.

In contrast, if the child wishes to adopt once he or she becomes an adult, that genetic risk is perceived as relevant information by adoption agencies. The guiding principle of the

agencies is the best interest of the adoptee child, and pilot research from the Oncofertility Consortium suggests that agency staff perceive cancer survivors to have a greater risk of illness or death during the adoptee's childhood than the average prospective adoptive parent (see Gardino, Russell, and Woodruff in this edition). Researchers could apply demographic modeling techniques to cancer survivorship and morbidity data to assess the validity of the agencies' concerns about survivors' likelihood of becoming ill again or dying compared to the general population of adults with similar demographic characteristics. Thus, cancer patients pursue fertility preservation because they perceive that avenue to parenthood as more certain than alternatives such as adoption.

Why Do Some Patients Pursue Fertility Preservation When It Is Unlikely that They Will Produce Usable Gametes or Survive to Use Them?

Value

Cancer patients may value fertility preservation methods, such as ovarian tissue cryopreservation, even when there is a low probability of their survival or the success of the procedure. Economics identifies several types of values that may be useful to understand this patient perspective. Value may be thought of as the measure of what someone would give to obtain something or require in order to let go of something; value may also be conceptualized as the utility that an individual gains from something. We assign use value to goods and materials that we use, such as personal clothing and cars. We also assign existence value to goods and materials that we do not use. For example, many people are happy to have a portion of their taxes provide support for federally funded parks and recreation areas such as Yellowstone National Park that they will never visit. But they gain value of some kind from the fact that the park is there to be used in theory. Cancer patients may gain a kind of value from the potential that they perceive in the ovarian tissue.

Normative Life Course

Cancer patients with uncertain survival may seek to reduce uncertainty in other areas of their lives. Fertility preservation may offer value in that arena as a way of maintaining the potential for biogenetic parenthood as a framework for the future after illness. Friedman, Hechter, and Kanazawa have noted the potential of childbearing as a strategy for uncertainty reduction [7]. Children are consumer durables so their presence provides a structural constraint of almost indefinite duration. The modern era of the late twentieth century was noted by Giddens [8] and other social theorists for its lack of societal cues to guide individuals in constructing their life narratives. In the 1950s, the constraints that sent mainstream Americans straight from high school or college into marriage and then a decades-long job for men or stay at home motherhood for women were stifling yet at the same time provided great security by answering huge questions about how to construct adulthood. The freedom that later generations experienced, and current generations are afforded, also creates anxiety. One way to master that anxiety is to generate limiting frameworks on oneself at the individual level, and having a child is a strong method for doing so. Following the decline in marital stability since the 1970s, the parent–child

relationship is possibly the most strongly institutionalized interpersonal relationship, particularly for women.

Reference-Dependent Preferences

Within behavioral economics, prospect theory proposes that individuals also assign unequal weights to probabilities, overweighting small probabilities and underweighting large probabilities [9]. In the case of oncofertility, the patient will therefore assign greater importance to the small probability of survival and less importance to the large probability that the fertility preservation procedure will not produce useful results (or conversely assign great importance to the small likelihood of being able to use the materials obtained through the procedure and less importance to the large likelihood of mortality). As seen in the pursuit of repeated *in vitro fertilization* (IVF) attempts by otherwise healthy individuals, patient behavior in this realm is generally to persist even in the face of great odds.

Prospect theory also suggests that we are more motivated to avoid loss than to achieve gain and that regret is a highly undesirable emotional state [9]. The least preferred outcome imaginable by the oncofertility patient is that she will fail to act to preserve her fertility and will then survive to a position in which she could have used the tissue or embryos obtained. A futile effort at fertility preservation still enables avoidance of a lost opportunity, an option that could have been available had one pursued a different course of action in the past.

Who Should Make the Decision about Fertility Preservation When the Patient Is a Minor?

Utility, Maximizing Behavior, and Altruism

Preferences shape individuals' utility functions. Utility is a measure of the relative satisfaction from, or desirability of, the consumption of various goods and services. Utilities across all goods and services are aggregated into a single functional form for each person, and then those curves may be further aggregated to represent the utility of families and societies. Individuals, families, and societies engage in maximizing behavior in order to derive the highest level of utility possible given circumstances such as the availability of goods and services and the resources that can be mobilized to attain them. Individuals who have positive preferences for children would thus incorporate children at a value of their own assignment into their utility function if doing so maximized utility. This incorporation occurs at the aggregated levels of family and society as well.

Not every individual and family will assign a positive value to future fertility. As noted above, from the perspective of Becker's new home economics, children are consumer durables, as they are not destroyed by use and are expected to have a long life span. Obtaining and investing in a child is a long-term commitment and involves extensive costs. (This perspective has been heavily critiqued [10] but it is a useful heuristic.) In the case of pediatric cancer patients, a conflict may arise between the preferences of the child

and the parents. One possible solution to the dilemma lies in parental altruism. Becker states that parents incorporate the child's utility function into their own [11]. Consequently, parental utility is maximized when their child's utility is also maximized. Since parents are of an age at which the maturity to consent is generally assumed, then parents should inherently make the best decision for their child, as they are presumably acting in a way to maximize their own utility.

Salience of Available Information

The age range of oncofertility patients spans from young children, of whom we can confidently say they are unable to give informed consent, to adolescents, whose cognitive and emotional development is in great flux, to young adults, who may still be financially and emotionally tied to their parents but who are legally formal decision makers. The diverse age range of these patients means that the level of information they can process and conceptualize about their true fertility preferences varies greatly.

Information is a central concept in economics, which classically focuses on the rational actor. Rational actors have a level of information about themselves, their situation, and their future. Based on this information, they make reasoned decisions. In the current case, information is highly problematic. First, information about how much one will enjoy parenting is always speculative until a child enters one's life. In the case of a minor, this information is even more tentative, given that the holder of the information is a child himself or herself, likely with little experience of caring for a dependent or having peers who are doing so. Decisions to parent are generally endogenous to marriage and education, and minors are unlikely to be married and likely still in the process of attaining their education. So future desires for a child are completely theoretical at age 4 (no information), highly theoretical at age 14 (possible experience babysitting and some idea of whether or not continuing education beyond high school), and somewhat theoretical at age 24 (normative "on-time" college graduation has or has not occurred, timing of entry into full-time work and first occupational status likely now observed, some romantic relationship experience, may have friends who have become parents).

Individuals also systematically expect their future preferences to be too close to their present preferences [12]. This tendency suggests that minors can be counted upon to misperceive their own wishes to have future children or to remain childless in comparison with grown women. This insight does not suggest that parents may be better at predicting for their child, but it is another strike against the child herself.

Time Preferences and Time Perspective

Economists note that individuals have time preferences when they engage in consumption. Because the here and now is more concrete than the hypothetical future, individuals assign a greater value to goods and services that they can have now rather than those that they must wait to obtain later. Thus, given the same item, we discount its value if we cannot have it in the present. For example, an apple today is worth $0.50; an apple tomorrow is worth $0.25; and an apple next week is worth $0.01, if an individual

were asked to pay for it right now. This model is useful for thinking in general about how oncofertility patients may have a demand for fertility preservation, but we need a developmental perspective to apply this model to the question of whether the minor or the parent should make fertility preservation decisions.

Psychologists approach this aspect of decision-making through the concept of time perspective, which assesses the influence of an individual's consideration of past, present, and future in their decision-making processes [13]. Time perspective is correlated with health behaviors in adults but the effects are tied to educational levels [14], which are still in process for children. Planning and control processes show a developmental pattern from the stages of childhood into adolescence and young adulthood [15], so an investigation of these psychological aspects of decision-making for oncofertility patients may provide useful evidence for bioethicists.

Should the Public Support the Provision of Fertility Preservation Procedures and Services?

Externalities and Public Goods

Economic theory is also useful to frame questions about whether society has an interest in whether or not a given individual reproduces. Society has a vested interest in supporting public goods: goods that, once provided, can be consumed by additional others at no marginal cost and goods with both positive and negative externalities (which are consequences of activities that are experienced by third parties, not those directly involved in a transaction). The positive externalities, or benefits, of children to society extend from their ability as a future generation of workers to provide a basis for taxation on which to fund the growth of transfer payments through Social Security and Medicare [16]. The future generation of children also provides our society with social reproduction by fulfilling their role as the next generation of "Americans."

Two imperfections exist in the creation of children at the societal level which have echoes at the individual level. First, certain children are worth more to society in terms of their future productivity and other children require remediational investment in order to reach this level [17]. Second, certain children are more pertinent to a society's social reproduction than others [18]. These societal problems translate down to the individual level as reasons for developing technology such as fertility preservation for cancer survivors. Using genetic material from others, having another carry the child, or adopting a child are viewed as inferior options because the quality of the child and the ability of the child to serve as a replacement for the parent in the next generation are both called into doubt.

But establishing the production of children as a public good also invites state regulation into the arena of reproductive practices. We accept as a principle of our system of government that states have the right to pass laws to address issues that are legitimately of interest and concern to the public [19]. Externalities create market imperfections that states use legislation to fix. For example, parks and recreation areas are public goods that

are not rational for a given individual to provide. Thus, states will use their powers of taxation to collect funds for them and then authorize government entities to construct and maintain them.

But while states are justified in using their powers to create programs such as Head Start to attempt to remediate the child quality problem at a societal level, the proposition that states have the justification to intercede at the individual level to influence which persons can reproduce biologically is highly contentious. Reproductive rights are constitutionally protected and states must have a compelling interest in order to override rights in that category. Economists have assessed the impacts of aggregated patterns of reproductive behavior on societal outcomes such as crime rates [20] and adult human capital [21], but they do not translate those findings back down to prescriptions for allocating access to reproductive technologies of any kind, from condoms to IVF.

Conclusion

This chapter highlights selected concepts from economics that researchers in oncofertility may find useful. Demography draws on a range of social sciences including sociology and anthropology, and bringing theories from these fields is likely to prove fruitful as well. While oncofertility brings together two fields of medicine, its practice is fundamentally grounded in the very social process of family formation, and its meaning to individuals and society can only truly be understood within that context. These economic concepts can help to shape the evolving discussion around fertility preservation for cancer patients, offering new perspectives on these important questions and strengthening the overall discussions in this field.

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