Mandating Coverage for Fertility Preservation — A Step in the Right Direction

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Connecticut and Rhode Island recently became the first U.S. states to pass legislation requiring insurance coverage of fertility-preservation services for patients about to undergo a medical treatment — surgery, radiation, or chemotherapy — that may have deleterious effects on the gonads. Although the World Health Organization considers infertility a disease, and both the American Society of Clinical Oncology and the American Society of Reproductive Medicine recommend that patients facing fertility-compromising (gonadotoxic) therapy be counseled about fertility preser-
vation and rapidly referred to reproductive specialists, insurance coverage for fertility preservation is rare. Critics have argued that fertility-preservation techniques are experimental or at least elective procedures, that cancer treatment does not always result in infertility, and that infertility is not life-threatening. But the cryopreservation of embryos, oocytes, and spermatozoa are established techniques. Rates of cancer-treatment–related fertility impairment range from 20 to 70%, and no patient chooses to get cancer and be rendered infertile by its treatment. And although infertility may not be life-threatening, fertility preservation is life-affirming, and consultation with a reproductive specialist results in reduced long-term regret and improved physical and psychological quality of life among patients with cancer.

The average cost in the United States of one fertility-preservation cycle of ovarian stimulation and embryo or oocyte cryopreservation is $12,737, and female cancer survivors cite cost as the most significant factor in their decision about pursuing fertility preservation. Complicating the situation is the fact that often gonadotoxic treatment must be started immediately after a cancer diagnosis, leaving patients no time to appeal to insurers for coverage of fertility preservation; once gonadotoxic treatment begins, the window for pursuing that option has closed.

Currently, 15 states (Arkansas, California, Connecticut, Hawaii, Illinois, Louisiana, Maryland, Massachusetts, Montana, New Jersey, New York, Ohio, Rhode Island, Texas, and West Virginia) require insurers to provide some coverage for diagnosis and treatment of infertility. In the other states, assisted reproductive technologies are considered elective treatments and not a required insurance benefit. But even in states with mandates, the current definition of infertility does not apply to fertility preservation. In Rhode Island, for instance, a majority of patients referred for fertility-preservation consultation do not qualify for coverage under the mandate’s definition of infertility and cannot afford counseling and treatment. Coverage is limited to women 25 to 42 years of age who are otherwise healthy, are married, and have been unable for 1 year to conceive or sustain a pregnancy. These restrictions, in addition to excluding women who are not currently “healthy,” may exclude young and unmarried women who have not yet attempted to start a family and potentially have the most to lose by undergoing gonadotoxic therapy. Finally, the mandate applies only to nongovernmental health plans that “include pregnancy related benefits,” thus excluding a large portion of reproductive-age patients. (This last restriction reflects the original 1989 language of the mandate, which remained in place even after the Affordable Care Act [ACA] was passed.)

As things stand, there is no market-based solution for fertility-preservation coverage. In states with existing insurance mandates, it may seem logical that insurers would save money in the long run by preserving fertility up front rather than covering repeated and frequently unsuccessful fertility treatments down the road. But since patients rendered sterile by cancer treatment would not undergo treatments covered in these states (since they would be futile), insurers have no incentive to bear the up-front cost of this preventive strategy. To its credit, one of Rhode Island’s larger insurers had recently introduced coverage for fertility preservation, but other insurers had not, and patients continued to face economic barriers to care while the critical window for fertility-preservation intervention closed.

Meanwhile, other conditions resulting from medically indicated treatments are generally covered by insurance. A comparable example is breast reconstructive surgery after lumpectomy or mastectomy, which remedies a consequence of breast-cancer treatment and significantly improves survivors’ quality of life. There is legal precedent for coverage of such iatrogenic conditions: the 1998 Women’s Health and Cancer Rights Act requires insurers that cover mastectomy to also cover the cost of breast reconstruction. We believe that insurers should view fertility preservation similarly, since infertility is a devastating consequence of cancer therapy and has a substantial effect on patients’ future quality of life.

In a time of scarce health care resources, some observers argue that insurance companies cannot support the financial burden of fertility-preservation coverage. However, the estimated incremental cost of providing such coverage to patients with breast cancer would be at most 10% of the cost of providing breast reconstruction. Even if 100% of women diagnosed with breast cancer who were undergoing gonadotoxic therapy pursued fertility preservation, the yearly cost for the entire country would be $126.6 million. Currently, only 4 to 10% of patients with breast cancer, the most common cancer in reproductive-age women, pur-
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Sue fertility preservation — at least partly because of lack of coverage. In the current landscape, a more accurate estimate of the total annual cost would be $3.8 million to $12.7 million — an amount that pales in comparison to the $1 billion required each year for coverage of breast reconstruction in the United States. With mandated coverage, utilization would probably increase, though perhaps not dramatically, since many patients would not have sufficient time before cancer treatment and others would already have had their children.

With these considerations in mind, we helped to craft the recent Rhode Island legislation, which is based on an alternative definition of “infertility.” We aimed to ensure that insurance policies provide coverage for medically necessary expenses “for standard fertility preservation services when a medically necessary treatment may directly or indirectly cause iatrogenic infertility to a covered person.” The legislation defines “standard fertility preservation services” as “procedures consistent with established medical practices and professional guidelines published by the American Society for Reproductive Medicine, the American Society of Clinical Oncology, or other reputable professional organizations” — thereby allowing for coverage of additional services as technology advances. It defines “iatrogenic infertility” as “impairment of fertility by surgery, radiation, chemotherapy or other medical treatment affecting reproductive organs or processes”; and treatment that “may directly or indirectly cause iatrogenic infertility” as “treatment with a likely side effect of infertility as established by the American Society for Reproductive Medicine, the American Society of Clinical Oncology, or other reputable professional organizations.”

There are two general approaches to legislatively mandating fertility-preservation coverage: establishing a new mandate defining fertility preservation as an extension of cancer treatment, or revising a current infertility coverage mandate by either redefining “infertility” (as Connecticut revised its definition to cover cases in which “such treatment is medically necessary”) or providing an additional definition for fertility preservation (as Rhode Island has done). The separate definition allows for explicit coverage of fertility preservation for iatrogenic infertility as part of medical treatment, without risking interpretation as an elective infertility benefit.

Other states considering establishing new mandates should be aware of potential resistance related to ACA provisions intended to discourage states from passing mandates that exceed the essential health benefits requirements. States, not insurers, must cover the cost of mandates passed after 2011, and if a mandate increases a plan’s premium, states must pay the difference. A potential alternative approach, particularly promising in states that lack an existing infertility mandate, is to revise an existing non-infertility-related mandate, such as one related to cancer (every state has at least one, including the Women’s Health and Cancer Rights Act). This approach has strong support from advocacy groups in various medical specialties (including oncology) that are jointly championing these legislative efforts through the Coalition to Protect Parenthood after Cancer.

Although this legislation is a step forward, many hurdles for equal access to care remain. The legislation applies only to private insurance companies, not governmental payers, and infertility coverage for men is limited. We hope that as more states enact similar legislation, all insurers, including Medicaid, will consider making their policies more inclusive. Though we recognize the challenges posed by the national economic and health policy environment, we hope other states will soon follow the lead of Rhode Island and Connecticut. As health care providers, we believe it’s our obligation to work to preserve our patients’ reproductive futures.

Disclosure forms provided by the authors are available at NEJM.org.

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