THE INHUMANITY OF FAIRNESS: RATIONING RESOURCES FOR RECONSTRUCTIVE BREAST SURGERY

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In Brief • En bref

The Dr. William Logie Medical Ethics Essay Contest is open to undergraduate medical students studying at Canadian universities. The contest, named in honour of Canada's first medical graduate, is sponsored by *CMAJ*. In the following essay, which won second prize in the 1994 competition, Dr. Agnes Wong examines how the state of Oregon reviewed the services it would insure under Medicaid, and why it determined that reconstructive breast surgery following mastectomy would not qualify.

Le concours Logie de dissertation en éthique médicale est ouvert aux étudiants en médecine du premier cycle qui fréquentent une université canadienne. Nommé en l'honneur du premier médecin diplômé du Canada, le concours est parrainé par le *JAMC*. Dans la dissertation ci-dessous, qui s'est mérité le deuxième prix au concours de 1994, le Dr Agnes Wong examine comment l'État de l'Oregon a passé en revue les services qu'il assurerait dans le cadre du régime d'assurance-maladie et les raisons pour lesquelles il a décidé de ne pas couvrir la chirurgie de reconstruction du sein après une mastectomie.

Mrs. G., 44, is married and has two children. Six months ago she detected a lump in her left breast that mammography and biopsy subsequently confirmed to be a malignant lesion. A week later a modified radical mastectomy was performed, and she was diagnosed with a stage IIb infiltrating ductal carcinoma. Coping with the lethal disease and the loss of her breast, Mrs. G asked her family doctor if she could have reconstructive breast surgery. The answer was no. Why? Because Mrs. G lives in Oregon, where reconstructive breast surgery after mastectomy for cancer is not paid for by Medicaid, a program that provides care for poor Americans. Since Mrs. G. comes from a working-class household she is unable to afford the procedure, and thus cannot have the reconstructive surgery.

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National health insurance is Canada's most popular social program. Because it offers comprehensive coverage and universal access, we do not yet have to deal with the kind of problem Mrs. G. is facing. However, as health care costs continue to rise we have witnessed a gradual reduction in the number of insured services. Quebec, for example, has removed services such as eye examinations (except for those aged 41-64) and children's dental care from its coverage.[1] As other provinces take similar steps, Mrs. G.'s problems may begin to appear less remote.

That Canada's health care system is based primarily on the notion of social justice is reflected in its key features: universality, comprehensiveness, accessibility, portability and public administration.[2] Unfortunately, the recent combination of economic slowdown and growing government deficits have placed great financial strain on our medicare system. Governments have sought new ways to meet health care needs in the face of limited resources, but some measures have met with strong public resistance. Former prime minister Kim Campbell withdrew user fees as a policy option during the last federal election for fear that it might cause a public uproar, revealing that measures that are perceived to threaten the underlying principles of the health care system are politically unpopular.

The Oregon plan, however, has generated a lot of interest among Canadian health care professionals and administrators who are considering its potential for determining which services should be included in our health care system. The Oregon plan embodies two major principles: limits on health care resources mean that not all health care needs can be met, and social values should be considered in evaluating services.

Oregon's state-wide attempt to reform the existing Medicaid program was implemented on Feb. 1, 1994. Its goal is to expand Medicaid coverage to more poor people while at the same time controlling costs by limiting the number of insured services. An independent commission was established to develop a priority list of health services based on benefit and cost, and to consult with the public about the social value of certain services. Available funds were then applied sequentially to the services on the list; those below the cutoff line were not covered.[3]

Can we adopt a similar plan? In Canada, health care has been regarded as a right, based on the principle of equality and justice. In essence, it holds that in a just society everyone

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should be treated equitably and fairly so that individuals can compete on an equal footing for the opportunities society offers.[4] Because health is a major determinant of a person's ability to compete equally with others, society should provide health care for all its members. Because resources are limited, however, not every health care need can be met. A just society should develop fair procedures for meeting important needs, while at the same time protecting equality and justice.[5]

Is the Oregon plan fair?

Is the Oregon plan consistent with the principle of equality and justice? Is it fair for Oregon to deny Mrs. G. reconstructive breast surgery?

Although this is a hypothetical case, it illustrates the plan's potential impact on breast-cancer patients. In Canada, breast cancer is the most common cancer affecting women; in 1993, about 5400 women were expected to die from it, while 16 300 new cases were expected to be diagnosed.[6]

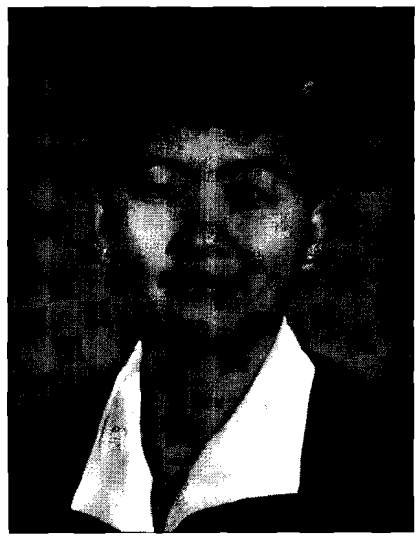
Mastectomy remains the main treatment, despite its association with a wide range of psychologic distress.[7] Four common psychologic sequelae have been observed: depression that lasts for months to years, lowered self-esteem, a diminished sense of femininity and womanliness, and anxiety caused by the potentially lethal disease.[8–11] A recent prospective study found that postmastectomy patients experienced varying degrees of anxiety (46%), depression (45%) and sleep disturbances (41%).[12] In addition, these patients' capacity for working was considerably reduced.[13]

Not only do breast cancer and mastectomy affect the physical and psychologic well-being of patients, but they also have a significant impact on patients' families. Klein points out that children may develop disciplinary and school problems in response to their mother's seemingly inexplicable depression.[14] Furthermore, marital difficulties and impairments in sexual relationships are often noted.[10,11] The husband may be concerned about his wife's survival and her feelings, but at the same time may find himself unable to help her as she withdraws because of feelings of helplessness and worthlessness. He may find the absent breast and the scarred chest repugnant; he may be puzzled about how he should pursue their sexual relationship, especially when she is withdrawing from him, apparently uninterested in sex.[14]

Reconstructive breast surgery helps these patients and their families by reducing the psychologic and physical impact of mastectomy. Women with breast reconstruction have shown substantial improvement in their psychologic, social and sexual adaptations.[7] This is further confirmed by studies that determined breast reconstruction is beneficial to a patient's feelings about her sexuality,[15,16] marital relations[17] and overall psychologic equanimity.[18]

Since reconstructive surgery is important to breast-cancer patients, why did Oregon exclude it from its health plan? According to the Oregon Health Services Commission, the decision simply reflects that cosmetic services have never been covered under Medicaid. It contends that breast reconstruction after mastectomy is a cosmetic service that is "nonessential" or "medically unnecessary." However, given the proven benefits of reconstructive breast surgery and the negative consequences of not providing it, how can Oregon justify its decision?

There is an important distinction between reconstructive surgery and cosmetic or esthetic surgery. Reconstructive surgery is concerned with the restoration or improvement of the form and function of *abnormal* or *deformed* structures, whereas cosmetic surgery is directed at the cosmetic improvement of *normal* body structures.[19] Few would disagree that cosmetic surgery is "nonessential." After all, society has no obligation to provide rhinoplasty to everyone who feels his or her nose is not perfect. However, denying reconstructive surgery to cancer patients has very different implications. Considering that reconstructive breast surgery can significantly improve the psychologic, sexual and social well-being of postmastectomy patients, is it really a cosmetic service? And if not, is it right for society to deny this procedure as an insured benefit to tens of thousands of women?



Dr. Agnes Wong

In defining what services are "essential," the Oregon commission primarily used criteria such as avoidance of death, medical effectiveness and prevention.[3] According to these criteria, breast reconstruction after mastectomy is nonessential because it does not directly affect mortality, is not effective in providing a cure or improving physical morbidity, and does not prevent breast cancer from recurring.

The problem is that these criteria ignore the quality-of-life issue. This not only explains why reconstructive breast surgery is not ranked high enough to be included in the health plan, but also why some rankings are obviously counterintuitive. For example, treatment for uncomplicated infectious mononucleosis is ranked higher than reconstructive breast surgery. Does this mean society is willing to pay for a condition that runs a self-limiting course and does not require any treatment, but is not willing to pay for surgery that could help Mrs. G and her family better cope with the stress caused by a potentially lethal disease?

(It should be noted that the commission originally incorporated quality-of-life measures to rank services, but the Department of Health and

Human Services believed that use of these measures could violate the Americans with Disabilities Act by devaluing health states that have residual disabling symptoms. Although it disagreed, the commission removed quality-of-life measures from its ranking in order to receive waivers to the federal Medicaid law that allowed implementation of the plan.[3])

The commission's contention that the decision to exclude reconstructive breast surgery reflects general attitudes or public preferences is open to two major criticisms. First, the community-meeting process did not involve a representative cross-section of society; almost 70% of participants were health care professionals and about 66% had postsecondary education.[20] The second is that although a list of social values was generated through the community meetings, it was not used in any direct way to determine priorities among health services, and some values were simply ignored.

A final consideration in excluding important services like breast reconstruction is the impact on accessibility, which is especially relevant in the Canadian context. It would mean that access to medical services would be influenced by income. As is frequently pointed out in the current health care debate, this could lead to a two-tier health care system in which the rich would be able to obtain excluded services while the poor could suffer because of their low incomes.

Conclusion

In addition to equality and justice, other principles such as respect for individual dignity and autonomy should be considered in order to evaluate thoroughly the ethics of the Oregon plan. In this paper I chose to focus on the principle of equality and justice, which is of most relevance to Canadians. I also narrowed the focus to look not at decision making at the macro level — such as whether it is more just to spend billions of dollars on a new fleet of helicopters than to allot much smaller sums for reconstructive breast surgery — but at whether, within the health care sector, the Oregon plan is ethically sound in allocating limited available resources.

Some may argue that we should not reduce health care coverage until all waste and inefficiency have been eliminated from the system. However, like the Oregon plan, this is only one of many options that our society can choose to meet health care needs in the face of limited resources. These options are not necessarily mutually exclusive; the crucial point is that no matter which we choose, determining whether it is ethically sound requires that we evaluate it by using the principles that are most important to our society.

Although the spirit or motive behind the Oregon plan was noble, its practical outcome does not measure up against some important ethical considerations. One problem is that little emphasis was placed on considerations such as quality of life. Another is that the process was not truly representative of the community. Finally, in what appears to be primarily a utilitarian approach to resolving issues of resource allocation, the plan seems to have inadvertently compromised such fundamental values as equality and justice.

It is impossible, of course, to balance utilitarian and deontologic considerations perfectly; nevertheless, a balanced outcome that is acceptable to both sides must be achieved. In the end, no matter how vigorous or sincere the process was, it is difficult to see how it is ethically acceptable for one of the world's wealthiest countries to refuse reconstructive breast surgery to a woman like Mrs. G.

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ECONOMIC HARDSHIP HAS PUT NICARAGUA'S HEALTH CARE SYSTEM ON THE SICK LIST

Patti Lane

In Brief • En bref

Since Nicaraguans elected a conservative government to replace the Sandinistas in 1990, hospitals and health clinics have seen their budgets slashed and staff cut, and medical supplies have grown scarce. The poor are dying of treatable illnesses such as pneumonia and other respiratory infections, and malnutrition and mortality rates are rising. This report from the Central American country outlines how economic hardship has taken its toll on Nicaragua's health system in the 1990s.

Depuis l'élection, en 1990, d'un gouvernement conservateur qui a remplacé les Sandinistes au Nicaragua, on a sabré dans les budgets et les effectifs des hôpitaux et des cliniques de santé et les fournitures médicales sont devenues rares. Les pauvres meurent de maladies curables comme la pneumonie et d'autres infections respiratoires, et les taux de malnutrition et de mortalité sont à la hausse. Ce rapport de ce pays d'Amérique centrale décrit comment les difficultés économiques ont ébranlé le système de santé du Nicaragua au cours des années 90.

Nicaraguan health expert Dr. Guillermo Gonzalez recounts the following story to illustrate how much the health care system in this Central American nation has deteriorated just 5 years after the end of Sandinista rule.

A Nicaraguan storekeeper recently brought her daughter to a hospital in the capital, Managua, from Esteli, a city 150 km to the north. The girl had measles, complicated by a respiratory infection. After 4 frustrating days she took her daughter home because the hospital couldn't treat her. It had no supplies, no serum, not even sheets for her bed. The woman thought that if her daughter died in Managua, it would be very complicated to take her body north for burial.

Because of funding cuts, hospitals cannot provide sufficient supplies. A patient is diagnosed, then given a list and told to go shopping. Patients must buy everything required for surgery, including sutures, gloves, scalpels, anesthetic and gauze, and their own sheets and bedding.

"Often patients who come to emergency [departments] leave because they can't afford to buy the required medicines and supplies," said Gonzalez, professor and former director of the School of Public Health at the Autonomous University of Managua.

Since Violeta Barrios de Chamorro's conservative government was elected to replace the Sandinistas in 1990, hospitals and health clinics have seen their budgets slashed and staff cut, and medical supplies have grown scarce. The poor are dying of treatable illnesses such as pneumonia and other respiratory infections, and malnutrition and mortality rates are rising.

The United Nations Index of Human Development, which is based on life expectancy, quality of life, level of education and income, illustrates Nicaragua's steady decline. In 1991 the country ranked 85th out of 174 countries, but by 1993 it had fallen to 111th. The economic hardships and budget cuts of the 1990s have chipped away at any gains made during the decade of Sandinista rule; the gains were made because when the Sandinistas came to power in 1979, President Daniel Ortega made socialized health care a priority.

"There was a huge increase in terms of investment in health services and a strong emphasis on preventive health and community-based health care," said Robert Fox, the Central American representative for Oxfam-Canada, an international aid organization.

The Sandinistas directed their efforts at preventive health care for the poor by opening primary health care posts in isolated, rural parts of the country, forming community brigades to implement mass-vaccination programs, restricting private medicine and reducing user fees.

By the early 1980s there had been important improvements in some health care indicators, according to data from another international relief organization, Save the Children. The infant-mortality rate was cut in half, to 61 deaths per 1000 live births, and by 1983 the number of medical consultations had tripled to 6.2 million a year. As well, vaccination campaigns eradicated such epidemic diseases as poliomyelitis.

But most gains were eroded as 10 years of war with US-backed Contra

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