Health Policy: Gaps in Access, Delivery, and Utilization of the Pap Smear in the United States

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CONCERN REGARDING CERVICAL CANCER MORTALITY has a long history which is tied closely to gynecology and maternal health. The fact that this is an accessible cancer site and that tumor formations are visible to the naked eye at advanced stages has contributed to its early recognition (Sand 1952).

Cervical cancer has been a significant cause of death among women and has been recognized as a contributor to mortality in mid-life. Much like maternal mortality, this disease has struck strong emotional chords in the population, and public demand for prevention and control has been frequent (Galdston 1937; Ringen and Kean 1986).

Emergence of cervical cancer as a public health problem is largely a twentieth-century phenomenon. Only 50 years ago little was known about cancer (Shryock 1979), and there was great pessimism about the potential for cervical cancer control measures (Ellwein 1978). Yet, in those 50 years, the death rate for white women has declined from greater than 10 per 100,000 females (Ellwein 1978) to less than 4 (Baquet et al. 1986), and the rate for all cancers of the uterus for white women has declined from about 30 (Ellwein 1978) to less than 7 (Baquet et al. 1986). While great progress has been made, however, major differences continue to exist between whites and blacks for both incidence and mortality. The rates for blacks are 2 to 3 times higher than for whites. The gap between these two groups has not narrowed (Baquet et al. 1986) as will shortly be described in more detail.

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The recognition that cancers are linked in many cases to social and economic disparities parallels the epidemic emergence of these diseases. In 1935 Brunet classified cancer together with alcoholism as being social diseases in the same way that infectious diseases like syphilis, tuberculosis, and leprosy were considered social.

Cancers of the uterus, by the nature of the differential patterns of incidence and mortality associated with race, ethnicity, and socioeconomic status clearly exhibit a sociological pattern. Thus, a policy review of cervical cancer control has to consider social welfare as much as individual behavior. The distribution of cervical cancer in the population also reflects the distribution of resources and needs—medical and otherwise—in our society, with regard to both causality and the degree to which diagnosed cancers are successfully treated.

Today, there are roughly 16,000 newly diagnosed cases and 4,000 deaths from cervical cancer in the United States per year (Sondik et al. 1987). In the overall scheme of health and disease in the population, this number of deaths is not high; it represents only about 1 percent of all cancer deaths. In some ways, it represents a great success. The decline of cervical cancer mortality is one of the most encouraging examples of cancer control (Ellwein 1978). Yet, much emphasis is given to this disease; it is included as one of the five specific objectives for cancer control in the United States for the period of 1985 to 2000 (Greenwald and Sondik 1986). Surely part of this emphasis stems from the fact that an effective control technology exists in the form of Pap smears for early detection. And just as surely, part of this emphasis stems from the largely unstated but intuitively accepted knowledge that today's deaths from cervical cancer represent a social inequity for which the public health professions share a sense of responsibility and a desire to overcome.

The fundamental policy questions that must be addressed with regard to cervical cancer are:

- How far toward eradication *can* society move? Iceland, with a homogeneous, very small, and extremely literate population (about 270,000), has been able to eradicate cervical cancer mortality for all practical purposes (Johannesson, Geirsson, and Day 1978). Thus, eradication can be theoretically achieved. In another long-term public health effort in British Columbia, however, the results have been impressive but not as encouraging. After actively screening

TABLE 1
Age-standardized Cervix Uteri (ICD-8: 180), Incidence Rates per 100,000 for Selected International Cancer Registries

Algeria (1966–1975)	24.1
Nigeria (1970–1976)	36.9
Swaziland (1979–1983)	28.2
United Republic of Tanzania (1975–1979)	9.4
Argentina (1980)	20.1
Bolivia (1978–1979)	57.8
Martinique (1981–1982)	34.6
Panama (1974–1980)	39.5
Fiji (November 1979–May 1982)	29.2

Source: Parkin 1986.
Note: U.S. age-standardized incidence rates per 100,000 for 1978-1981 were: 8.8 for whites and 20.2 for blacks (SEER program).

since 1949, the age-adjusted mortality rate has dropped from 11.5 in 1955 to 4.8 in 1974 per 100,000 women over 20 years of age (Boyes et al. 1977). According to a leader of this effort, this may be the best that can be accomplished (Boyes 1984). In practical terms, what then should we expect as a minimum level of feasible control in the United States, with its large size, heterogeneous population, and cumbersome medical care system?

- How far toward eradication is society *willing* to move? This political question is outside the realm of this article and is resolved only though the equitable allocation of resources. The willingness to spend on cervical cancer control ultimately is indicative of the extent to which society is willing to spend resources on the needs of the disadvantaged.

Indeed, cervical cancer is a mirror of—or represents in microcosm—social development. It is a sentinel event for a broader public health problem (Howard 1987). Today, it increasingly mirrors the inequity in resource distribution between rich and poor countries, between north and south. More and more, cervical cancer is emerging as a major cause of death in major female population segments in developing countries, where incidence rates may be 3 to 5 times the rates for white American women (table 1) (Waterhouse 1982). This reflects, in part, the ability to control infectious diseases, the ability to diagnose

and register cervical cancer (which is inexpensive), and the inability to treat (which is expensive). Thus, the gap between black and white—poor and nonpoor—in the United States—and what to do about it—and the gap between poor and rich nations have many parallel features. Therefore, while this article is about the United States, its broader extension and relevance should be obvious.

A Conceptual Model for Cancer Control

The paths to prevention are traditionally conceptualized as either primary or secondary. Primary prevention activities address risk factors that predispose the individual to cancer development. Reduction in these risk factors should result in a reduction in cancer incidence.

Secondary prevention activities address risk factors that predispose to mortality without affecting incidence directly. Thus, the focus is on enhancing the duration of survival after a cancer diagnosis through improved detection, diagnosis, and treatment. Mortality rates are influenced by both changes in incidence rates associated with primary prevention strategies and in survival rates associated with secondary prevention methods.

This article does not deal with primary prevention of cervical cancer for the following reasons:

- Etiologic data on cervical cancer are not consistent and the excess risks identified for any particular risk factor are relatively low (Hulka 1982).
- The major risk factors that have been suggested—notably sexual practices, poor hygiene, and viral infections—are not readily addressed by categorical prevention programs. At least, to date, no categorical cervical cancer prevention programs exist to be drawn on as examples.
- The reductions in incidence rates in Western nations that have taken place in the last four decades cannot be accounted for by any specific public health effort. Rather, they are probably associated with general socioeconomic development which has afforded better health practices in general, such as nutrition and hygiene as affected by both social change and greater citizen awareness (Devesa 1984).

Secondary prevention efforts will be dealt with extensively. The main model that is used draws on the tradition of health services research (Myers 1965). The major risk factors for cancer mortality that are addressed by secondary prevention can be categorized as: access, availability quality, continuity, and compliance with regard to the delivery and use of health and medical care services.

The paths to cancer prevention and control may be general and population-wide or they may be targeted at special population segments where risk is great. These are trade-off considerations that are made—often implicitly—in policy. A relatively small level of change in either incidence or mortality distributed over a broad population base may have a greater effect in terms of absolute numbers than a large level of change in a small population segment. Cervical cancer control clearly falls into the category where targeted approaches directed at high-risk populations are required.

Cervical Cancer in the United States

Epidemiological Classification Problem

There are inconsistencies in the classification of cervical cancer data, which may affect some of the analysis of this problem:

Numerator Problems. Although microscopic confirmation of all diagnoses now exceeds 98 percent for both whites and blacks in the United States, 7 to 9 percent of all histologic classifications are unspecified carcinoma (Baquet et al. 1986). A more significant problem may be the classification of premalignant (dysplasia) and noninvasive malignant diseases (e.g., cervical intraepithelial neoplasia [CIN]) as early stages or carcinomas in situ, or vice versa. It is not probable that late stage cancers are affected significantly by pathologic classification problems.

Denominator Problems. The use of different population denominators may affect incidence and mortality rates greatly. There are at least three broad approaches to defining the denominator:

1. All females regardless of age. (This dilutes the denominator by including children and adolescents.)

2. Mature females. Typically, this definition will include all females above an arbitrary age cut-off, usually either age 16 or age 20.

3. One of the two above with the additional qualification of "having an intact uterus." With rates for total hysterectomies in the United States approaching 30 percent or more of mature females, this has become an important consideration. For instance, one study in Los Angeles has suggested that 25 percent of the decline in cervical cancer mortality may be attributed to the increased performance of total hysterectomies (Stern et al. 1977).

The basis for defining the denominator is rarely discussed when cervical cancer rates are presented. This could be a very serious confounder in comparative studies of incidence and mortality rates domestically as well as internationally.

Adjustment and Standardization Problems. Cancer rates are typically reported as age-adjusted or standardized to some reference population at a particular time period. While this is convenient for the summary of large data sets to indicate time trends, the simplification can result in reduced accuracy. Two problems are especially noteworthy with regard to the population selection on which standardization is based:

1. Lack of sex differentiation. Often, age standardization may be based on the entire population (as the denominator), male and female. This presents clear problems when the cancer site studied is limited to one sex, such as for cervical cancer.

2. Lack of race differentiation. Given that life expectancies vary between races (U.S. Department of Health and Human Services 1985), it would seem worthwhile to standardize or adjust rates by race. Rarely is this done, however.

Age-specific and race-specific rates are, therefore, preferred to standardized or adjusted rates when attempting to understand, particularly for policy purposes, patterns of cancer in the population. Figure 1 presents age-specific incidence and mortality rates for cervical cancer in whites and blacks in the United States. While the age-specific rates are lower for whites than for blacks in all age categories, there are very dramatic increases in both incidence and mortality rates in older-

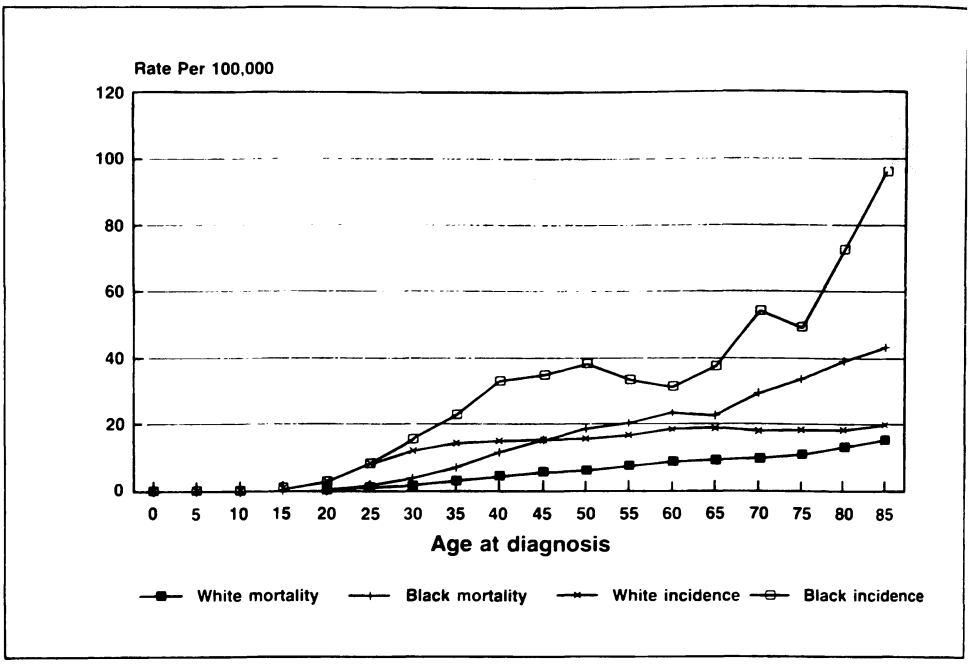

FIG. 1. Cervix uteri incidence and mortality by race, 1980–84.

aged blacks, while the rates remain more stable for whites after age 30. Given the latency periods associated with cervical cancer, sequential age-specific cohort analysis may be important to monitor changes in social and behavioral patterns (related to policy initiatives or otherwise) and how these might affect rates in different age groups in the future. The use of age-standardized or adjusted rates would not provide a clear understanding of these nuances.

Descriptive Cervical Cancer Statistics

The following data are derived from the National Cancer Institute SEER (Surveillance Epidemiology and End Results) program, a population-based cancer incidence and survival reporting program which involves eleven population-based tumor registries. This program is described in detail elsewhere (Sondik et al. 1987; Baquet et al. 1986). The following data refer only to invasive cervical cancer. They do not include in situ cases.

Age-adjusted Incidence Rates, 1975 to 1984

Black females have higher age-adjusted incidence rates when compared to their white counterparts (table 2). Age-adjusted cervical cancer incidence has decreased in black and white females during the period of 1975 to 1984. Although decreases have occurred for both groups—and more so among black women than white women—black women continue to have higher incidence rates. During this period incidence rates decreased by 41.4 percent (6.1 percent annually) in blacks and 25.8 percent in whites (a 4.0 percent annual decrease). In 1975 age-adjusted incidence was 27.6 per 100,000 population in black females compared to 11.0 in whites. In 1984 incidence was 16.0 and 8.1 in black and white females respectively.

Age-specific Incidence

Age-specific incidence rates have decreased also during 1975 to 1984 for most age groups for both blacks and whites. The age-specific rates for invasive cervical cancer, however, increases more for blacks as age advances. Black women have over 200 percent higher incidence than whites in the 70-plus age category.

Age-adjusted Mortality, 1975 to 1984

Cervical cancer mortality is also higher in blacks. In 1975 the age-adjusted mortality rate was 11.0 per 100,000 in blacks and 3.9 in whites. Although decreases have occurred during the referenced time period, differences in mortality persist. In 1984 the mortality rate for blacks was 7.5 per 100,000 compared to 2.8 in females. During the period of 1975 to 1984, the age-adjusted mortality rates for both blacks and whites declined by roughly the same proportion, that is, 27.8 percent and 28.1 percent respectively (table 3).

Five-year Relative Survival

The five-year relative survival rate for the time period of 1974 to 1982 was 61.2 percent for blacks and 68 percent for whites (table 4). Survival differences also exist within stage (extent of disease) for blacks and whites. Caution is advisable when interpreting these rates

TABLE 2
Cervical Cancer Age-adjusted Cancer Incidence Rates, 10-year Trends, 1975-1984 (per 100,000 population)

	Year of diagnosis										Average annual percentage change	Percentage change
	1975	1976	1977	1978	1979	1980	1981	1982	1983	1984		
Black	27.6	24.2	22.4	19.2	23.5	18.9	18.4	18.0	14.3	16.0	−6.1%	−41.4%
White	11.0	10.7	9.6	9.3	9.1	8.9	7.9	7.7	8.0	8.1	−3.9	−25.8

Source: National Cancer Institute. Surveillance, Epidemiology and End Results (SEER)

TABLE 3
Cervical Cancer Age-Adjusted Cancer Mortality Rates, 10-year Trends, 1975-1984 (per 100,000 population)

	Year of diagnosis										Average annual percentage change	Percentage change
	1975	1976	1977	1978	1979	1980	1981	1982	1983	1984		
Black	11.0	10.6	10.0	9.5	8.8	8.9	8.1	8.0	8.0	7.5	−4.2%	−27.8%
White	3.9	3.9	3.5	3.4	3.3	3.1	3.1	2.9	2.8	2.8	−4.0	−28.1

Source: National Cancer Institute. Surveillance, Epidemiology and End Results (SEER)

TABLE 4
Percentage of Cervical Cancer Five-Year Relative Survival Rates, by Historical Stage, 1974-1982

	All stages	Localized	Regional	Distant	Unstaged
Black	61%	84%	44%	17%	59%
White	68%	88%	50%	12%	68%

Source: National Cancer Institute. Surveillance, Epidemiology and End Results (SEER)

since they are based on small samples of cancer patients (1,840 blacks, 8,857 whites), a problem which is even more severe when the cases are disaggregated by stage.

Risk Factors for Secondary Prevention

It is possible to identify some factors associated with the adequacy (or inadequacy) of secondary prevention strategies as practiced today. For example, in 1970 a national survey of women under the age of 45 who had ever been married found that approximately 10 percent had never had a Pap test. The rate of those never having had a Pap test was twice as high in the black population as in the white population. Having had a Pap test was significantly related to education and family income (Rochat 1976). Based on data from the 1973 National Health Interview Survey, Kleinman and Kopstein (1981) concluded that among all women the group least likely to report having had a Pap test was that of poor black women living in nonmetropolitan areas. Among the women in this group, 25 percent of those aged 25 to 44 reported never having had a Pap test, 50 percent of those aged 45 to 64 reported never having had a Pap test, and 68 percent for those aged 65 and over. In two retrospective studies of women diagnosed with cervical cancer in the 1970s, screening history and patterns of health care were examined. Fruchter, Boyce, and Hunt (1980) reported that 52 percent of the women in a Brooklyn, New York, study had no previous Pap test and that 62 percent had no Pap test in the previous 5 years. Walton and Kernodle (1979) reported in their study of Eastern North Carolina that only 12 percent of women diagnosed

with cervical cancer had previously received a Pap test. Even though 62 percent of the women had been exposed to the health care system for some medical care service in the recent past, they had not received a Pap test. Another study reported reasons given to outreach workers regarding why high-risk women in California mass-screening programs refuse to participate. Most of the replies related to lack of convenience, indicating that the women probably did not feel that cervical cancer was a great risk or that cervical screening was worthwhile (Misczynski and Stern 1979). Alternatively, a report on work-site cervical cancer found that convenience of screening is a significant factor that influenced participation rates, and that (at least in Australia) the workplace may be a good place to conduct screening because of its convenience for working women (Raphael 1977).

The Potential for Cervical Cancer Control

As the previous section indicates, cervical cancer incidence and mortality rates have declined steadily during the past 30 years (Devesa 1984). Nevertheless, disparities continue to exist between whites and blacks for both incidence and mortality rates. The differences for incidence are approximately two-fold, while the differences for mortality are about three-fold. The magnitude of the differentials has not declined appreciably during this period. Nor can the difference in mortality rates be accounted for by the differences in incidence rates alone; among incident cases blacks clearly experience poorer survival rates than whites. There are no apparent host or biological explanations for why the cervical cancer survival differences persist. Consequently, a substantial reason appears to be the inequitable distribution of health and medical resources (i.e., quality treatment) between blacks and whites.

The Value of Earlier Detection

About one-third of cervical cancer cases detected are at stage II or higher. Given the significantly reduced survival associated with the more advanced stages, there clearly is room for improvement. The significantly poorer rates that blacks experience further suggest that

targeted approaches to early detection and follow-up could produce improved survival.

Programs of screening and early detection can have a significant impact even where the baseline of cervical cancer incidence and mortality are low. The Scandinavian countries exemplify this. These homogeneous, socioeconomically advanced populations are served by national health systems that have significantly eliminated the problem of access to and availability of health care services. Nevertheless, within Sweden there has been a marked decline in advanced-stage disease associated with cervical cancer screening (Stenkvist et al. 1984). Among the Scandinavian nations, cervical cancer mortality rates in Norway have not declined as rapidly as in the other Scandinavian nations. Norway was alone in not instituting vigorous programs of cervical cancer screening (Day 1984). This suggests that it should be possible to accelerate the decline in advanced-stage disease for both whites and blacks in the United States through targeted aggressive promotion of cervical cancer screening.

Critical Factors in Secondary Prevention

Analysis of factors that have contributed to avoidable mortality from cervical cancer is fairly complete. The main risk factors for poor survival include the following:

Lack of Pap Smears. The Pap smear has been well established by scientific concensus and extensive research to be an effective and efficacious detection tool with a high degree of predictive value (National Institutes of Health 1980). The strongest predictor for cervical cancer being diagnosed at a late stage is the lack of a Pap smear being offered in the last five years before diagnosis. In a case control study in Baltimore, a three-fold odds ratio was identified for this factor (Celentano et al. 1985). Much of this problem relates to access to care, for there is a clear association between having had a Pap smear and having a regular source of care and health insurance coverage. Even among those with complete access, however, such as members of prepaid group practices, there have been differentials in the reported use of Pap smears. Minorities seem to have received fewer Pap smears (Breslow and Hochstim 1964; Warneke and Graham 1976; Graham et al. 1972). To what extent that is accounted for by patients' behavior, and to what extent provider behavior is responsible, remains undetermined.

Source of Care. Several studies have found source of care to be another critical factor. Two concerns are noted. In terms of diagnosis, never having seen an obstetrician/gynecologist has been associated with advanced-state cancer diagnosis with an odds ratio of 3.4 in Baltimore (Celentano et al. 1985). For treatment following diagnosis, in one study in Buffalo, N.Y., survival was better for patients treated by gynecologists and surgeons and by doctors who had treated many cervical cancer cases. Expertise and experience also seemed to be an important characteristic of the hospital/institution providing the treatment (Graham et al. 1972). This problem can be related to the needs of high-risk women, based on a recent study of emergency rooms and sexually transmitted disease (STD) clinics. In either case, availability of gynecologic services was an exception. As a consequence, Pap smears are not routinely offered as part of the pelvic examination in STD clinics (Marcus et al. 1986).

Lack of Continuity. Because risk of advanced stage cervical cancer is associated with low income and lack of health insurance coverage, the highest-risk individual often must rely on emergency rooms, public health clinics, and outpatient departments for care. This pattern of care raises obvious concerns about continuity of care. This problem is being studied in Los Angeles. Preliminary data on follow-up of 419 abnormal Pap smears taken in hospital clinics or emergency rooms between December 1984 and July 1985 are now available (A.C. Marcus, University of California, Los Angeles, Jonsson Comprehensive Cancer Center, personal communication). Only 54 percent of the women with abnormal Pap smears received adequate follow-up. In interviews with the patients not receiving follow-up, the reasons given for this failure in medical care delivery were: financial reasons (28 percent); not informed about need for follow-up (18 percent); patient was told she was O.K. (13 percent); too busy to participate/comply (13 percent). The two strongest predictors of nonfollow-up were severity of Pap test results (the worse the result the lower the follow-up likelihood) and the nature of the clinic. The rate of nonfollow-up ranged from 30 percent to 66 percent depending on the clinic. This study is now testing an intervention strategy to improve follow-up, which suggests that with relatively minor efforts aimed at improving administrative procedures in clinics, personalized communication with the patient and transportation, major improvements can be made. These interventions, however, are not a substitute for identifying

means to overcome the financial barriers that now exist for needed medical care services.

Quality of Laboratory Practices. The Pap smear is a detection tool, not a diagnostic procedure. Increasingly, the laboratory reading of slides is being conducted in specialized cytopathology laboratories, often on a mail-order basis. In the 1970s the Centers for Disease Control conducted a laboratory proficiency study to establish the quality of these laboratories (Yobs, Swanson, and Lamotte 1985). This study found significant variations among laboratories including: (a) lack of standardized criteria and classification systems for reading slides and reporting results; (b) inadequate smears being taken and prepared; and (c) cytopathologic reading error. For these reasons, it is likely that error rates may exceed 10 percent.

Policy Considerations

When considering strategies to reduce cervical cancer mortality, two distinctions need to be made: (a) strategies to reduce cervical cancer mortality in general in the population, and (b) strategies to reduce the gap in mortality rates between whites and minorities. In this article we are concerned mainly with reducing cervical cancer mortality in the black population.

Race or Economic Disadvantage

There is no known inherent host or biological reason that would explain the excessive cervical cancer rates experienced by blacks. Articles elsewhere in these volumes document both the demographic structure of the black population—including its disadvantage relative to the white population for a variety of socioeconomic factors—and the problems that blacks face in seeking access to the health care system. Recently, the American Cancer Society (1986) issued a report which assigned preeminence to economic disadvantage as a major factor explaining the differentials in cancer incidence and mortality rates between blacks and whites. Economic disadvantage certainly can be related to some of the differentials. It does not, however, explain all of the differentials in cervical cancer rates between blacks and whites. In fact, a major study of 3,802 invasive cervical cancer cases among white women and

954 cases in black women found that income and education could account for two-thirds of the incidence difference (Devesa and Diamond 1980). Likewise, as we have noted earlier, receiving routine Pap smears is not dependent on access to care alone; even in prepaid clinics black women have had lower Pap smear rates in the past (Breslow and Hochstim 1964) and probably still do today. Clearly, factors other than socioeconomic status are related to cervical cancer incidence and mortality and have yet to be identified by well-designed analytic (rather than descriptive) studies. Additionally, the exact nature of the relation of income or socioeconomic status to cancer has not been characterized.

Maternal Mortality—A Useful Model

The application of the history of maternal mortality control as a model for secondary prevention of cancer has been set forth elsewhere (Ringen and Kean 1986). In the 1930s, responding to the alarming rate of deaths during childbirth, particularly in the immigrant tenements, public health and preventive medicine activists initiated through their professional organizations measures to define the causes and propose interventions to reduce them (Galdston 1937). The first of these studies was conducted in the five boroughs of New York City under the auspices of the New York Academy of Medicine. Every case of maternal death was tracked down and analyzed by an expert committee in accordance with established standards of maternity (and perinatal) practice. The committee found that 66 percent of the deaths could have been avoided, and that, of these, 61 percent could be ascribed to provider error and the remaining 39 percent to patient error. A maternal mortality committee was established to review each case in the future and to recommend corrective actions (New York Academy of Medicine 1933). Soon similar committees were established in other communities, and before long maternal death rates began a dramatic decline toward eradication.

Although it would be naive to suggest that this model has direct application to the complexities entailed in cancer control, it provides many useful guidelines, especially related to the control of cervical cancer. First, by conducting the studies in defined populations, the scientific *and* demonstration impacts were maximized, and, as an example, strongly influenced the inclusion of Title V in the Social

Security Act of 1935 for support to perinatal hospital care and other remedies for maternal and infant mortality. Second, the use of the in-depth retrospective case analysis proved useful to the analysis of relatively rare events in communities. Third, the use of the expert committees to establish standards of care and review case material proved to be a powerful vehicle to bridge the gap between scientific and research expertise, on the one hand, and, on the other hand, public health action responsibility. This is not a perfect model. The science was somewhat crude. And in the long run it is unclear whether the continued presence of permanent maternal committees serves a useful purpose. But there can be no doubt that their initial value was great in terms of documenting the problem, setting standards of practice, and demonstrating that improvements could be made, and that this model is useful in the context of control of cervical cancer (and other cancers) today (Breslow 1984).

Some Principles for Cervical Cancer Control

There are some basic principles that apply to cervical cancer control:

- Cervical cancer is a relatively rare event in the population, including among black women. For that reason, a case-finding/management approach seems an essential tool, and it is for this reason the maternal mortality model holds great appeal as an example.
- Cervical cancer is a "non-contagious" disease. Consequently, there is no constitutional basis for applying the police powers of the state for public health purposes, and there is no basis for compulsory approaches to controlling the disease. This clearly complicates the use of the case-finding/management approach.
- In the absence of compulsory authority, as well as in light of the limitations on financing and access to medical care, there is no basis on which to propose population-based screening in the formal sense of the word "screening," that is, the ability to achieve complete case ascertainment.
- Early detection, as implied in screening, is not the only issue involved in reducing avoidable cervical cancer mortality. A broad range of activities directed at early detection, continuity, improved quality, and compliance are required. This means that a strategy

aimed broadly at secondary prevention is more useful than a strategy simply based on screening for early detection.

- To the extent that cervical cancer mortality is avoidable, it must be recognized that both providers and individuals at risk have responsibilities. Recognition that cervical cancer is symptomatic of long-standing and deep-rooted problems in the relation between medical care provider and medical care consumer is essential.

Recommendations

Within the framework suggested above, a number of recommendations can be made which should help reduce the rates of cervical cancer mortality. These recommendations exclude approaches to medical care financing and improvements in access to care since others in these volumes cover these subjects extensively. Our concern is with improving the delivery and use of detection and follow-up services.

Service Delivery. The following changes could be made immediately without changes in financing:

- Pap test recommendations. Table 5 records the major sets of recommendations that now exist with regard to Pap testing. None of these sets is identical, and there is a great deal of confusion about the best recommendations. Of particular concern is the widespread belief that Pap testing should not apply to elderly women or women over the age of 60. The age-standardized data on cancer in figure 1 clearly indicate that this is not an appropriate recommendation. Black women, in particular, experience high rates of both incidence and mortality after the age of 60, and should continue to receive Pap smears regularly, even after menopause. The respective professional societies should achieve agreement on this subject immediately.
- Laboratory standardization and quality control. After more than 30 years of cervical cancer detection with the Papanicolaou smear, it should be possible to reach agreement on standardized nomenclatures for classification, cytopathology proficiency testing, and general laboratory quality control. As there is a great deal of concentration in the number of active cytopathology laboratories processing Pap smears, this task should have been made less complicated technically (although perhaps not politically). There

TABLE 5
Current Pap-Testing Recommendations

	National Cancer Institute 1983[a]	American Cancer Society 1980[b]	American College of Obstetricians and Gynecologists 1980[c]	NIH Consensus Development Conference 1980[d]	Canadian Task Force 1982[e]
Age to begin Pap tests	Onset of sexual activity	20 or at onset of sexual activity if earlier	18 or at onset of sexual activity if earlier	Onset of sexual activity	18 if sexually active
Age to discontinue Pap Tests	None specified	65	None specified	After 2 negative smears after age 60	60 (unless never specified)
Frequency	After 2 annual negative smears, every 1 to 3 years	After 2 annual negative smears, every 3 years	Annual	After 2 annual negative smears, every 1 to 3 years	Annual for ages 18–35, then every 5 years

Sources: Adapted from Weisman et al. 1986.
[a] National Cancer Institute 1983.
[b] American Cancer Society 1980.
[c] American College of Obstetricians and Gynecologists 1980.
[d] National Institutes of Health 1980.
[e] Walton, R.J. 1982.

can be little doubt that the laboratory error rates could be reduced significantly, and this again is within the purview of the professional societies.

- Improve outpatient detection. Adoption of Pap smear practices in emergency rooms, outpatient clinics, and public health clinics is more an administrative problem than an economic problem. By assigning one person the responsibility for oversight of Pap smear practices and follow-up of nonnegative cases, a great deal of improvement can be made in individual clinics. And there is no justification for sexually transmitted disease clinics not performing a Pap smear when performing a routine pelvic exam (Marcus et al. 1986).
- Improved inpatient detection. A large proportion of women who are diagnosed with cervical cancer have been hospitalized for other reasons in the immediate years preceding diagnosis without receiving a Pap smear. This presents a special opportunity for improved detection, especially in older women who no longer have regular gynecologic care, or who are uncomfortable about having outpatient pelvic examinations. It also provides the opportunity to assure better rates of follow-up than may be the case in the outpatient setting, where contact with individual patients—especially those at highest risk—may be hard to maintain. One estimate from New York State suggests that 53 percent of the deaths from cervical cancer for the years 1967 to 1969 might have been prevented had it been assured that hospitalized women received "routine" cytologic testing (Greenwald, Nasca, and Gordon 1972).

Data Needs. Extensive data exist to describe the cervical cancer patterns in the United States. Nevertheless, data needs exist, especially in the following areas:

- Uniform definitions of numerators and denominators. For numerators, agreement on how to classify and include early lesions is especially important; this relates to the pathology classification systems above. For denominators, the age groups—especially the lower age cut-off needs to be standardized. Also, denominators should control for varying rates of total hysterectomies, which has emerged as a major secular trend in the last thirty years.
- Analysis by stage of disease. Rather than reporting overall rates,

rates by stage of disease would be more useful for policy purposes. Because advanced-stage disease is associated with the poorest survival, this is a major concern to policy formulations that seek to reduce mortality. At the same time, however, analysis of data by stage reduces the number of cases and, thereby, the statistical power significantly, which suggests the need for innovative ways of aggregating data geographically or over time.

- Age-specific reporting. Age-specific rates may be more useful to policy development than age-adjusted or age-standardized rates, since these methods tend to dilute age-related variations. For instance, we have noted that recommendations for Pap testing have "cut-offs" at ages 60 to 65 in many cases. Clearly, the age-specific rates for black women, in particular, indicate the need to eliminate this cut-off, something that age-adjusted or age-standardized rates would not indicate.

Basic Research Needs. There is a critical need to conduct studies on the contribution of transmittable viral agents and viral titers in relation to cancer prevention and control. Human papilloma virus studies would be useful. Of concern is carrier status and transmission for *both* men and women, and the potential for vaccine development to control this risk factor. A major area in need of both laboratory and analytic epidemiology study is the identification and control of precursors to advanced disease.

Research in Prevention and Control—Applied Epidemiology. Rigorous studies are needed to test intervention strategies in controlled settings. Although a large number of studies have been conducted to test various aspects of cervical cancer control measures, there is a serious lack of well-controlled, population-based studies in the United States. The Centers for Disease Control (Center for Environmental Health) and the National Cancer Institute (Division of Cancer Prevention and Control) both support a number of studies, mainly directed at urban black populations. Ultimately, there is a need to develop rigorous studies to document the level of mortality reduction that can be achieved realistically in the United States. Areas in need of special emphasis include:

- Adherence. Testing of different recommendations to determine

which achieve optimal provider and patient adherence. Of special concern is the frequency of Pap testing.

- Follow-up and continuity. Ways to assure follow-up of suspicious and positive test results in patients seen in outpatient or clinic settings need study. Another area in critical need of continuity research is the change in the pattern of medical care delivery that women experience in mid-life, and how this affects Pap testing practices.
- Special population segments. Populations in need of special emphasis in terms of cancer control interventions include, in addition to blacks, the following: native Americans, whose rates approximate those experienced by blacks; older women who stop using gynecological services; and rural populations, for whom little research has taken place.
- Alternative delivery modes. The significance attached to convenience in effective detection programs and the problems of maintaining continuity in follow-up and over time suggest the need to explore alternative approaches to delivering detection services. The possibility of offering Pap testing as part of occupational medical services needs to be studied at a time when participation by women in the work force is growing. Organizing programs within the auspices of social service agencies, child care centers, churches, etc. have been suggested as means to providing, promoting, or offering referral to detection and treatment services. The need to determine the potential coverage by such programs is critical. It is just as important to know who such programs will reach effectively as who they will not reach.

Conclusions

Although a relatively rare event, cervical cancer demonstrates a clear social inequity between blacks and whites. While a significant proportion of this inequity can be attributed to blacks being overrepresented in the low socioeconomic categories compared with whites, low socioeconomic status cannot explain the entire disparity. There does not appear to be any inherent biological reason for the differences in cervical cancer rates between blacks and whites. Consequently, race as a sociological factor must be implicated.

For incidence rates the difference is about two-fold. For mortality rates, the difference is about three-fold. While these rates for both blacks and whites have declined over time, the differentials have not changed much. This suggests that both the socioeconomic and racial discrimination factors that may account for these differences have persisted over time.

The need for special efforts aimed at cervical cancer control should remain a public health priority. A broad range of measures need to be implemented, including changes in classification systems for pathology, improved laboratory standardization, proficiency testing and quality control, and delivery of services. It is apparent that many changes that would improve detection and follow-up care could be implemented at little additional cost, such as changing procedures in outpatient clinics and inpatient settings and providing Pap smears in sexually transmitted disease clinics. Such efforts would be likely to benefit black women especially because of their lower frequency of Pap smears and greater reliance on outpatient clinics and emergency rooms.

It is not possible to predict the impact of an effective public health program of cervical cancer in the United States today. By one estimate in New York State based on data from the late 1960s, however, the simple practice of assuring that all hospitalized women received Pap smears (and were followed up) could reduce deaths from cervical cancer by 50 percent (Greenwald, Nasca, and Gordon 1972). Thus, a benchmark of reducing cervical cancer death rates by 50 percent is conservative in the overall population, and very conservative in the black population where the base-line of avoidable mortality is highest.

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