

Cancer and Sexual Minority Women

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1 Introduction

1.1 Issues and Trends

Cancer is the leading cause of death in the United States, outpacing deaths due to heart disease. During the year 2005, an estimated 1,372,910 persons in the United States were expected to be diagnosed with cancer, and 570,280 persons were expected to die from it—more than 1500 people per day (American Cancer Society, 2005). These estimates do not include noninvasive (in situ) cancers and most skin cancers; new cases of skin cancer are estimated to exceed 1 million per year (American Cancer Society, 2005). About three-fourths of all cancers occur in people age 55 and older (American Cancer Society, 2005).

After adjusted for normal life expectancy (accounting for factors such as dying of heart disease, injuries, and other diseases of old age), a relative 5-year survival rate of 64% is seen for all cancers (American Cancer Society, 2005). This rate means that the chance of a person recently diagnosed with cancer being alive in 5 years is 64% of the chance of someone not diagnosed with cancer. Five-year relative survival rates commonly are used to monitor progress in the early detection and treatment of cancer and include persons who are living 5 years after diagnosis, whether in remission, disease-free, or under treatment. Currently almost 10 million people in the United States are cancer survivors (American Cancer Society, 2005) and more than half of the cancer survivors are women (National Cancer Institute, 2003). Therefore, the number of sexual minority women who are cancer survivors is likely to be considerable. In addition to the human toll of cancer, the financial costs of cancer are substantial (Brown et al., 1996; American Cancer Society, 2005). These costs include the financial cost of cancer treatment and/or survival (essentially, costs for health care provision and for long-term care due to disability) and the financial costs of cancer due to economic loss of individuals who work less or leave the workforce due to cancer (Yabroff et al., 2004).

These data allow us to make two points. First, cancer is a relatively frequent disease that takes a toll on the population's health. Therefore, it is likely that cancer takes a toll on the health of sexual minority women as well. Whether it affects sexual minority women disproportionately is the topic of much discussion, but a definitive answer is still unknown. Second, there are opportunities for both improving the quality of cancer treatment and survivorship for the general population and for identifying opportunities for testing and disseminating methods to prevent cancer from occurring and for detecting it early. It is likely that sexual minority women could benefit from these opportunities as well as the general population.

1.2 Disparities in the General Population

The cancer burden is unequally distributed in the population in that different demographic and socioeconomic characteristics are linked to cancer-related disparities. The American Cancer Society links the following characteristics to disparities: "income, race/ethnicity, culture, geography (urban/rural), age, sex, sexual orientation, literacy" (American Cancer Society, 2004, (p. 21)). For instance, death rates vary by gender (Wingo et al., 1999) in that lung cancer death rates in men have declined since 1990 yet have increased among women for several decades until recently when they reached a plateau (American Cancer Society, 2005).

Racial and ethnic minority groups have lower survival rates than Whites for most cancers (Jemal et al., 2005). All racial and ethnic groups, except Asian/Pacific Islander women, are more likely to die from all cancers combined within 5 years of diagnosis compared with Whites (Ward et al., 2004; Jemal et al., 2005). African American women are about 20% more likely to die of cancer in general than are Whites, yet they are twice as likely to die of stomach or cervical cancer than Whites (Jemal et al., 2005). African American women are more likely to die of breast and colon cancers than are women of any other racial and ethnic group (Ward et al., 2004). The incidence also differs among ethnic groups in that Asian Americans/Pacific Islanders have the highest incidence of stomach, liver, and intrahepatic bile duct cancer, Hispanic women the highest incidence of cancer of the cervix, and African American women the highest incidence of colon, rectum, and stomach cancer (Ward et al., 2004). Across all racial or ethnic groups, persons who live in more affluent areas have higher survival rates than do those in poorer areas (American Cancer Society, 2004; Ward et al., 2004).

These disparities in cancer incidence, survival, and mortality rates represent a challenge to understand the reasons that cause them. Healthy People 2010 calls for the elimination of these disparities to improve the nation's health (U.S. Department of Health and Human Services, 2000). We know that complex interactions of social, cultural, and economic factors cause cancer disparities, yet disparities as they relate to sexual minority women have yet to be identified in population-based data, and the factors that cause them must be carefully

examined. The challenge of detecting factors of cancer disparities related to sexual minority women is further compounded by the fact that sexual minority women are also of different race/ethnicity, age, socioeconomic status, religion, and education, providing additional complexities in understanding subgroups of sexual minority women.

1.3 Definition of Sexual Minority Women

Different labels for sexual minority women are used in the literature cited in this chapter because of the diversity of labels, identities, and sexual behaviors investigated in the research. The issue of measuring sexual orientation status has received attention in the theoretical and empirical literature (Laumann et al., 1994; Young & Meyer, 2005). For this review we use the term “sexual minority women” (SMW) to refer generally to lesbian, gay, and bisexual women. When possible we use the term SMW to describe the general group of women.

Typically, this definition also includes transgender individuals; however, existing research on cancer does not generally focus on this population. As a result, in this discussion we do not include transgender individuals under the general description of SMW and, instead, refer to them separately in the text. Research studies on SMW sometimes group lesbians and bisexual women together because of their overlapping sexual practices whereas at other times separate them when sexual behaviors differ (Johnson et al., 1987). As a result, lesbian and bisexual are terms we use in addition to SMW when a study’s focus dictates this distinction. We define *lesbians* as “women whose emotional, social, and sexual relationships are primarily with women” (p. 315) (Phillips-Angeles et al., 2004). The lesbian identity, like other sexual orientations, encompasses different dimensions, including sexual identity or how one self-identifies, the sexual desire or attraction a person feels for another, and sexual behavior (Bonvicini & Perlin, 2003). *Bisexual women*, as described by Tucker and Colleagues (1995), have the potential for attraction to both men and women and are attracted to the individual rather than a person of a particular biologic sex or gender (Tucker et al., 1995).

2 What is Known About Cancer Incidence and Risks in Sexual Minority Women?

2.1 Cancer Rates Among Sexual Minority Women

Little is known about potential cancer incidence disparities in SMW owing primarily to the lack of collection of appropriate data in national registries and databases. MEDLINE searches crossing the cancer site by homosexuality, female, and lesbian (October 26, 2005) provided no comparative population-based incidence data. Possible disparities regarding the health status of lesbians and possible barriers to access to health services by lesbians have been identified by the Institute of Medicine (IOM) as a research priority (Solarz, 1999). The January 2001

newsletter of the Mary-Helen Mautner Project for Lesbians with Cancer points out that “each year 23,000 women are diagnosed with ovarian cancer, and 14,000 die from the disease, making it the deadliest of the gynecologic cancers and the fifth leading cause of cancer death among women” (Boyd, 2001). Several investigators have hypothesized that SMW have a higher breast cancer incidence than heterosexual women. A small-scale study found higher rates of breast cancer among SMW; but because the cohort was small and the research methodology was not population-based, the reliability of these findings has been questioned (Dibble et al., 1997). One study found a higher risk of breast cancer among lesbians using a reasonable sample (Kavanaugh-Lynch et al., 2002). None of the existing studies has been truly population-based, as are the cancer incidence publications for the United States (Greenlee et al., 2000).

A Danish group found similar rates of cancer between SMW and heterosexual women using a registry approach, where same-sex marriage-like relationships are registered as well as heterosexual marriages (Frisch et al., 2003). However, the median age of the female registry participants at the time of registry was 37, leaving a relatively small sample at the older years, when cancer is more prevalent. SMW receive less frequent gynecologic care than heterosexual women (Robertson & Schachter, 1981) and therefore might be at greater risk for mortality and morbidity from a range of gynecologic cancers. Both of these risks are likely compounded by the difficulties many SMW experience in communicating with or receiving standard clinical care from physicians and health care systems.

Each year more women die from lung cancer than breast cancer (American Cancer Society, 2004). Lung cancer rates are likely to be higher in SMW owing to smoking differences (summarized below), although data on incidence and prevalence are lacking. The three most common cancers in women—breast, lung, colon—were expected to claim the lives of more than 140,000 women during 2005 (Jemal et al., 2005). Little is known about the prevalence and incidence of other cancers among SMW, and more research is thus needed. Even less is known about cancer in transsexual persons, and research is thus needed to determine rates, risk factors, and screening needs (Balén et al., 1993; Lawrence, 2005).

2.2 Risk Factors for Common Cancers Among Sexual Minority Women

Risk factor levels or risk factors themselves may differ between SMW and heterosexual women. However, published population-based data on these risk factors are sparse. The hypothesis that SMW have higher rates of breast cancer came about because of the potential higher rates of risk factors such as obesity, alcohol consumption, and null parity (Denenberg, 1995; Haynes, 1995) in addition to lower screening rates. Although definitive studies in this area have yet to be completed, data on the prevalence of each of the risk factors confirm the plausibility of this hypothesis (Dibble et al., 1997; Valanis et al., 2000; Cochran et al.,

2001; Case et al., 2004). There are risk factors for ovarian cancer that are common among all women (e.g., personal or family history of ovarian, breast, and colon cancer; increasing age), but there is discussion that SMW may be at increased risk for ovarian cancer as well (Boyd, 2001). Among the risk factors responsible for this possible increased risk are lower frequency of childbearing, lack of oral contraceptive use, lack of access of health care, lower utilization of the health care system, and possibly the use of fertility drugs (Boyd, 2001).

The single exception to the striking lack of data on risk factors for cancer among SMW is in the area of smoking. Smoking is the most important risk factor for lung cancer and many other chronic diseases; SMW are more likely than heterosexual women to use tobacco products, as documented in reviews and population-based studies (Diamant et al., 2000; Valanis et al., 2000; Cochran et al., 2001; Gruskin et al., 2001; Ryan et al., 2001; Case et al., 2004; Tang et al., 2004). Data collected using strong methodology have documented approximately double the rates of smoking for SMW compared to heterosexual women in California (Tang et al., 2004; Burgard et al., 2005). This single risk factor difference could account for up to one-third of disparity-related deaths, given national estimates on the impact of smoking on health. No intervention studies are published, but one such study is ongoing at the University of California, San Francisco (2005); and the American Legacy Foundation (2005) is supporting community intervention for LGBT adults in several major cities in the United States. These activities are encouraging starts at reducing the behavioral disparity of smoking use by SMW.

3 Primary and Secondary Prevention Opportunities

3.1 Primary Prevention in Sexual Minority Women

Evidence suggests that several types of cancer can be prevented and that the prospects for surviving cancer continue to improve. The ability to reduce cancer death rates depends, in part, on the existence and application of various resources, in particular the means to provide culturally and linguistically appropriate information to the public and to health care providers on primary prevention actions, such as changing or reducing behaviors known to increase the likelihood of developing cancer. It is estimated that 50% or more of cancers can be prevented through smoking cessation and improved dietary habits, such as reducing fat consumption and increasing fruit and vegetable consumption (U.S. Department of Health and Human Services, 1990; Willet, 1996). Physical activity and weight control can also contribute to cancer prevention (Greenwald et al., 1995; U.S. Department of Health and Human Services, 1996). These are all relevant to SMW owing to differences in the behavioral characteristics of this group.

As previously discussed, tobacco use is clearly higher among SMW than among heterosexual women. Given the importance of tobacco use in causing most major diseases and premature deaths, this is a critical

disparity that needs research attention. Unfortunately, little has been published on methods to reduce this disparity in SMW.

Considerable literature has linked healthy dietary behaviors, physical activity, and more recently obesity to rates of several cancers. One review concluded that obesity levels were higher in SMW than in heterosexual controls (Bowen & Balsam, 2005). The small literature comparing dietary behaviors and physical activity between SMW and heterosexual women indicates poorer dietary quality and lower rates of overall physical activity. The literature in these areas is sporadic and poorly sampled, and therefore it is difficult to draw reliable conclusions from the available articles.

3.2 Secondary Prevention and Sexual Minority Women

Data suggest that mammography, the best proven breast cancer screening method to date, is used less frequently by SMW. There are few population-based studies, but regional and local surveys of SMW and reasonable comparison samples indicate 10% differences in mammography rates between these two groups (Valanis et al., 2000; Bowen et al., 2004; Case et al., 2004). Although there are no national data on rates of mammography among SMW and transgender populations, the existing data indicate that a possible disparity by sexual minority status may exist. Access barriers may inhibit appropriate mammography screening, and specific interventions should be designed for both providers and patients to increase access to mammography screening. Breast and cervical health programs funded by the Centers for Disease Control and Prevention (CDC) may serve as a potential model for replication in sexual minority communities, but no evaluation data on these programs have been published. After such a program was implemented, a reduction in breast cancer deaths could be expected to occur after a delay of roughly 7 years (Fletcher et al., 1993).

Evidence shows that a reduction in colorectal cancer deaths can be achieved through detection and removal of precancerous polyps and treatment in the earliest stages of the disease. The findings from randomized, controlled trials indicate that biennial screening with fecal occult blood tests can reduce deaths from colorectal cancer (Mandel et al., 1993, 1999; Hardcastle et al., 1996; Kronborg et al., 1996; Winawer et al., 1997). The U.S. preventive services task force recommends annual tests, with follow-up endoscopy for those with positive screens. We have no data on rates of colon cancer screening among SMW.

To reduce the number of cervical cancer deaths, a high percentage of women in the United States aged 18 years and older must comply with screening recommendations. Evidence from randomized preventive trials is unavailable, but expert opinion suggests that a beneficial impact on cervical cancer death rates would be expected to occur after a delay of a few years. There are no national data on Pap test rates among women of sexual minority orientation or nonconformative gender identity. Recent survey data suggest lower Pap test rates among lesbians (Diamant et al., 2000). This lack of established medical care could lead to higher rates of cervical cancer, and research is needed to

identify methods for reducing this disparity. Issues regarding access to appropriate care could be one explanation (Cochran et al., 2001) and should form the basis of interventions to improve provision of care. Little or no population-based data on lesbians, bisexual women, or male-to-female (MtF) transgender people are obtained through national-level surveys or studies.

Cancer has been related to human papilloma virus (HPV) infection. Data indicate that sexual behaviors between women can result in HPV transmission (Marrazzo, 1996; O'Hanlan & Crum, 1996), and there is some indication that SMW and their providers may not perceive women who have sex with women as an at-risk group, contributing to a lack of Pap tests among SMW (Marrazzo, 2004). Similarly, gay men, who are at higher risk for anal cancer, often do not receive preventive care, including Pap tests. Therefore, it is likely that SMW do not receive adequate care as well.

For MtF transgender individuals, the belief among many providers that they are still biologically male may interfere with preventive gynecologic care. Also, tissue remaining after sex reassignment may still produce cancer cells. Female-to-male (FtM) transgender people who have a cervix remain at risk for cervical cancer and require regular Pap tests. However, there are no existing data on actual risk. Specific guidelines for recommended prevention efforts have not been developed, but the Harry Benjamin International Gender Dysphoria Association (HBIGDA) recommends that transgender persons be screened for malignancies "as are all other persons" (Association, 1998). MtF transsexuals who have undergone vaginoplasty also may not be perceived as being at risk. However, persons who have undergone penile-inversion vaginoplasty with the penile gland retained as a neocervix should be offered neocervical Pap tests because of the risk of penile cancer in this group (Lawrence, 2005).

4 What of the Future? Research on Cancer in Sexual Minority Women

The above discussion illustrates the dearth of data to guide policy and practice in the area of cancer prevention and control in SMW. Here we list areas of immediate need for research into this area.

4.1 Call for Research into Cancer Risks and Risk Factors for Sexual Minority Women

More research using innovative methodologies and standard registries is needed to determine differences in cancer risk and risk factors for SMW. For example, a cohort design using studies of records in New York and California cancer registries and the National Death Index found gay and bisexual men to be at excess risk for anal cancer, non-Hodgkin's lymphoma, and Hodgkin's disease. These data accounted for an increased risk for all cancers in this population. The authors found no difference in the incidence of cancers at any other site, including lip, oral cavity, and pharynx; digestive system and peritoneum;

respiratory system; bone and connective tissues; skin; genital and urinary organs; bone marrow (multiple myeloma); blood and tissues (leukemia); or other and unspecified sites (Koblin et al., 1996). This type of design could be implemented with SMW to identify increased risk of all types of cancer.

Population-based national data sets, such as Surveillance Epidemiology and End Results (SEER), could include sexual orientation in specific circumstances and could encourage the publication of data using sexual orientation as a subgrouping variable. Current examples of national public health surveys that do include sexual orientation are the National Health and Nutrition Examination Survey, the National Survey of Family Growth, and others that are tracked at <http://www.gaydata.org>. Individual states are now including sexual orientation on selected Behavioral Risk Factor Surveillance System surveys, but this does not provide us with a national picture. Once this simple, easily collected variable is in place in multiple surveys, risks and risk factors for a variety of diseases could be identified for SMW.

4.2 Call for Research into Prevention in Sexual Minority Women

Mechanisms or systems must exist for providing SMW with access to state-of-the-art risk assessment, preventive services, and treatment. Where suitable, application for participation in clinical trials should be encouraged. A mechanism for maintaining continued research programs and for fostering new research is essential. New information on genetic markers or environmental linkages that can be used to improve disease prevention strategies and healthy behavior counseling is emerging for many cancers and may provide the foundation for improved effectiveness in clinical care and preventive counseling services.

There is a continuing and vital need to foster new partnerships for innovative research on both the causes of cancer (including genetic and environmental causes) and on methods to translate biologic and epidemiologic findings into effective prevention and control programs through publicly funded programs and community organizations (Lasker et al., 2001), and research with SMW is no exception (Durfy et al., 1999). This research can provide new opportunities for cancer prevention and control in the future and further reduce many burdens associated with cancer. This need can be met, in part, with the network of cancer control resources now in place, as it has the organizational and personnel capacity for various cancer interventions. Despite the extent of these resources, they alone are insufficient to reduce deaths from cancer. Gaps exist in information dissemination, information on optimal practice patterns and clinical guidelines, research capabilities, and research underway in other countries. These gaps must be recognized and filled to meet cancer prevention and control needs.

Rigorous evaluation of interventions that target SMW for screening and health behavioral change interventions comprise the most critical gap in the literature. For example, a pilot study evaluating the feasibility of a didactic session to encourage cancer screening among lesbians (Dibble & Roberts, 2003) ended with a call for a carefully

evaluated study in this area. Few other research on interventions to improve the health of SMW have been published (Bowen et al., 2006) but much more is needed to provide evidence-based ideas for public health and clinical practice changes. Intervention research involves first identifying the changeable risk factors, developing methods to support change in these risk factors, and conducting rigorous research to identify the ability of these interventions to change the targeted behaviors. Previously mentioned intervention research and public health practice to reduce smoking among lesbian, gay, bisexual, transgender (LGBT) communities is a cutting edge example of intervention opportunity. As disparities are identified, we must move more quickly to intervention research to reduce or eliminate them.

4.3 Research Needs Regarding Treatment and Survivorship of Sexual Minority Women

For all cancers, treatments proven to increase survival are needed along with improved access to state-of-the-art screening and postdetection care. In addition to measurements of survival, indices of quality of life for both the short term and long term are important considerations. Appropriate treatment relies on full access to care, which is likely lacking in SMW. Therefore, this could form another area of need for both research and practice improvement. Although we have no good data on the cancer treatment SMW receive (Dibble & Roberts, 2002), it is possible that differences in cancer treatments may exist that influence SMW's survival. Studies of the general population with cancer indicated that differences in treatment exist; for example, patients who are older are less likely to receive aggressive therapy (Goodwin et al., 1993, 1996; Ballard-Barbash et al., 1996; Silliman et al., 1997), as do patients who are uninsured (Ayanian & Guadagnoli, 1996; Roetzheim et al., 2000; Bradley et al., 2002; Voti et al., 2005). We do not know if potential treatment disparities for SMW is due to aspects of the provider–SMW patient relationship that interfere with treatment adherence or to provider prescription itself. Furthermore, lesbians are likely to express interest in complementary and alternative therapies (Bowen et al., 2002; Matthews et al., 2005), and how this affects SMW's choices and preferences for standard treatment and adjuvant therapy should form the basis of research in the future.

Coping with and responses to cancer, including cancer survivors' perceptions of well-being, have been widely researched, and interventions to improve cancer survivors' psychosocial outcomes have been developed. Similar studies of the social context and the psychosocial outcomes of SMW with cancer are mostly lacking (Fobair et al., 2001, 2002; McGregor et al., 2001; Boehmer et al., 2005b). Although there are sparse data on long-term follow-up of SMW cancer survivors and their social context, it is reasonable to suggest that several factors may affect survivorship. Social support through partners and friends rather than family, a lack of community support, health care access barriers, and barriers in provider–patient communication may jeopardize the adjustment of SMW diagnosed with cancer and their long-term survival. One

study determined that lesbians were less frequently partnered, yet were more likely to obtain social support from their partners and friends than heterosexuals (Fobair et al., 2001). Another study found that almost one-fourth of SMW with breast cancer did not have a significant support person to rely on and suggested that relationship status may be of importance for the availability of such a person (Boehmer et al., 2005a). The single intervention study with SMW breast cancer survivors indicated that emotional distress can be reduced and the coping of SMW can be altered; yet SMW reported also a decline in the level of their social support after the intervention (Fobair et al., 2001). Additional research is needed to verify that these are barriers and to design appropriate solutions to improve SMW's well-being and to increase their survival.

4.4 General Research Needs in This Area

Difficulty assessing sexual orientation in the general population may lead to bias in any existing studies on LGBT participants and their risk for various cancers. Available studies typically use study respondents who live in urban areas and are perhaps more open about their sexual orientation, usually of midlife age. It is not known to what extent the results are applicable to the less "out," older, or younger SMW populations.

There has been little research concerning cancer among transgender persons. One population-based study from The Netherlands suggests that overall cancer morbidity and mortality rates among transsexuals are comparable to those of the general population (van Kesteren et al., 1997). Nevertheless, transsexuals' exposure to hormone therapy over an extended period of time might be expected to increase the risk of certain hormone-related cancers. For example, estrogen is a risk factor for cancer of the breast, and there have been four case reports of breast cancer in MtF transsexuals treated with estrogens (Symmers, 1968; Pritchard et al., 1988; Ganly & Taylor, 1995). There have also been two case reports of ovarian cancer in FtM transsexuals, and it has been suggested that testosterone therapy may be a risk factor for such cancers in FtM transsexuals (Hage et al., 2000). These case reports might welcome follow-up research attention.

There are no national data on the degree to which physicians and dentists recommend preventive measures or deliver clinical preventive screens for cancer among LGBT patients. However, there is a significant amount of data, cited in other chapters, to suggest that SMW are less likely to have health insurance and have limited access to appropriate care, including culturally appropriate health education materials, cancer screening, and prevention counseling. There is also evidence that health care providers from a variety of disciplines are uncomfortable providing care to SMW and therefore may not address their specific needs or even general prevention strategies.

The negative impact of homophobia and heterosexism cause much more than a lack of population-based data on LGBT persons and SMW's cancer-related disparities, respectively. They also cause a lack

of recognition of LGBT persons as a population subgroup with a shared culture consisting of “customs, beliefs, values, knowledge, and skills that guide a people’s behavior along shared paths” (p. 14) (Gay and Lesbian Medical Association & LGBT Health Experts, 2001). Although we need population-based data to measure the magnitude of the cancer burden in SMW, we also need research that seeks to examine SMW’s culture to understand how to reach this population appropriately and effectively for cancer-related messages and provide cancer-related care. Many of the disparities outlined in this document could be linked to cultural differences between SMW and heterosexual women. For example, there is some consideration of body image and perceptions that could prevent SMW from feeling comfortable with providers who do not understand issues of sexuality and gender roles prevalent in SMW (Boehmer et al., in press). These cultural issues deserve more research attention and could form the basis of a research program that could benefit SMW and contribute to the larger field of gender studies.

There are currently a wide variety of demonstration projects that provide services to SMW in large urban areas living with cancer. These cancer projects provide services for survivors of cancer and other chronic diseases. There is no available research on the efficacy of these projects, but their continued wide use and availability speaks to the role they fill in communities.

5 Summary

Cancer is a serious health issue for many people, including LGBT persons. Research suggests that some risk factors for cancer are more prevalent in sexual minority women than heterosexual women, and sexual minority women may be disproportionately affected by some cancers, including breast cancer, lung cancer, and cancers caused by HPV. Data are needed on rates of risk factors and cancers in sexual minority women, with participants identified by sexual orientation in population-based research efforts and data surveillance systems. Heterosexism and homophobia in the health care system may make LGBT persons less likely to receive needed prevention information and treatment, putting them at risk of higher cancer-related morbidity and mortality. Finally, public health programs to improve health behaviors to prevent cancer are lacking for sexual minority women. Therefore, research is needed to determine culturally appropriate methods of prevention- and treatment-oriented interventions for sexual minority women, so targeted health education, care services, and planning policies can be implemented.

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