

Disability Status

Introduction

According to 2005 data from the U.S. Census Bureau, 15.5 percent of California adult women living in the community have disabilities, or 2.1 million women; among women 65 years and older, 42.1 percent have a disability.¹ An additional 87,000 California women with disabilities live in institutions such as nursing homes, or about 0.7 percent of adult women.² As the population ages and as the life expectancy of women with disabilities is increasing,³ the number of women aging with disabilities is growing.⁴ Very little, however, is known about the cancer experience of women with disabilities. To date, the literature on breast cancer among women with disabilities has almost entirely focused on issues related to screening, and to a lesser degree, treatment. There remain critical gaps in our knowledge of breast cancer in this large segment of the U.S. population.

The dearth of information on breast cancer among women with disabilities is reflective of a more general neglect of research interest in the health of people with disabilities. Historically, most public health resources have focused on preventing disability in the healthy population, rather than promoting health among people with disabilities.⁵ In the early 1990s, the glaring absence of baseline data on people with disabilities was highlighted by the U.S. government's report *Healthy People 2000*.⁶ Nine years later, in its follow-up report,⁷ the Center for Disease Control and Prevention (CDC) for the first time set out specific goals addressing the health and well-being of people with disabilities: 1) promote health of adults with

disabilities; 2) prevent secondary conditions among people with disabilities; 3) eliminate health disparities between people with and without disabilities.⁷ In response, there has been considerable research in the last five years on health promotion efforts targeting people with disabilities. Now is the ideal time for breast cancer researchers to seize this momentum and build upon these efforts to lessen the burden of breast cancer among this large and growing segment of the population.

Concept/Exposure Definition

The concept of disability has evolved over time. Thirty years ago, disability referred solely to an underlying physical, cognitive, or psychological impairment or health condition. Today, disability is conceptualized as a combination of the condition, the individual's ability to function in various domains, and the interaction between the person and the environment in a way that enhances or prevents full social participation.⁸ Disability is usually defined according to the presence of functional or activity limitations, which are part of the definition used by the Americans with Disabilities Act (ADA), and in population surveys such as the CDC's National Health Interview Survey (NHIS) and Behavioral Risk Factor Surveillance System (BRFSS), and the U.S. Census Bureau's Survey of Income and Program Participation (SIPP) and American Community Survey (ACS). These surveys, which offer widely divergent prevalence estimates of disabilities in the U.S. population according to the particular questions asked, were designed to capture a broad population with any type of activity or functional limitation. More traditional

measures of disability identify limitations in Activities of Daily Living (ADL), which are self-care activities such as bathing or dressing; limitations in Instrumental Activities of Daily Living (IADL), which are activities often associated with independent living, such as going out to shop or to a doctor's visit; and limitations in a person's ability to work.⁹ The World Health Organization, striving to codify a standard classification of disability, developed the International Classification of Functioning, Disability, and Health (ICF). Since an individual's functioning and disability are considered to depend, in part, on the person's environment, the ICF does not provide a single way to determine disability status. Instead, the ICF suggests a classification scheme to define disability in the context being studied.¹⁰

In the context of studying the impact of breast cancer on women with disabilities in the U.S., it clearly is necessary to define disability in a variety of ways, depending on the research question being studied. Unfortunately, however, there has not been any systematic approach to identifying the pertinent definitions of disability status with respect to the various breast cancer outcomes of interest. Even breast cancer studies designed to address the same research question have had little consensus on the definition of disability. Some studies have focused only on long-term disabilities such as deafness or blindness,^{11, 12} while others have utilized the more traditional definitions focused on ADL and IADL, which may include both long-term and short-term disabilities.¹³ Disabilities associated with chronic medical conditions such as obesity or severe asthma are often, but not always, included in the disability

literature. Consideration of cognitive/developmental disabilities separate from physical disabilities is likely to be of critical importance,¹⁴ as is consideration for the degree or severity of disability and how it impacts mobility.¹⁵⁻¹⁷ Other studies use Medicare eligibility or receipt of Social Security Disability benefits as a de facto definition of disability among non-elderly women.^{18, 19} Such a definition can be faulted for two reasons. First, it excludes many women with significant disabilities who may not qualify for these benefits, either because their disability does not meet the restrictive Social Security definition based on inability to work, or because they lack sufficient work histories. Second, it includes some women without disabilities who qualify for benefits for reasons other than disability, such as the transfer of benefits from a deceased parent. A functional measure of disability, though often not available in the datasets being analyzed, would be far superior to using program participation as a proxy for disability status.

In summary, there is a clear need to systematically identify the population of women with disabilities of particular interest when performing research related to specific aspects of breast cancer. When available, existing data should be used to inform such studies. As discussed below, it is likely that even within one area of the breast cancer continuum, it will prove useful to sub-categorize disability to better pinpoint the sources of disparities between women with and without disabilities.

Biologic Plausibility

There is no observed overarching unifying mechanism by which “disability” directly affects breast cancer risk. The question has not even been asked yet about whether there is overlap between genetic markers for breast cancer and genetic markers for specific disabling conditions. However, research on breast cancer among disabled women stands to offer unique insights into the disease. Perhaps the best example of biologic plausibility arises from the small body of literature on breast cancer among blind women. The observation that blind women appear to be at a reduced risk of breast cancer led to what is now known as the ‘melatonin hypothesis.’²⁰ This hypothesis states that women who are blind, by virtue of having no light stimuli, have high levels of melatonin, which, in turn, reduce breast cancer risk. This hypothesis has spurred an entire area of breast cancer research which has offered important clues into both the etiology and treatment of breast cancer (see Section I, Chapter H, on Light at Night). By neglecting the breast cancer experience in the large segment of the U.S. population with any type of disability, we may be overlooking important clues into the disease’s etiology.

Critical Review of the Literature

Prevention

Primary breast cancer prevention could take the form of exercise, chemoprevention (such as the use of tamoxifen or raloxifene),²¹ prophylactic oophorectomy, or prophylactic mastectomy.²² There have been no studies of the degree to which

women with disabilities engage in these preventive strategies.

Many of the factors that have been established to influence risk for breast cancer (e.g., age at menarche, age at menopause, parity, age at first birth, family history) are difficult, if not impossible, to modify. Behavioral factors (e.g., alcohol consumption, physical activity, breast-feeding), which should be more amenable to change, have also proved fairly resistant to modification, at least at the individual level. Some macro-level primary prevention activities recently have been proposed by Willett and colleagues.²³ Included in these recommendations are changes to society’s infrastructure, which can help promote physical activity and healthful eating habits; development of social norms for low alcohol intake by women; and facilitation of childcare and breast-feeding for working women.²³ In addressing these and other potential breast cancer prevention strategies, the accessibility needs of women with disabilities need to be considered.

Primary breast cancer prevention that focuses on reduction of behavioral risk factors in general has been the subject of a small number of intervention development studies in populations of women with disabilities.²⁴⁻³⁰ These interventions addressed the needs of women with physical disabilities and took the form of face-to-face workshops, generally employing psycho-educational and behavior modification approaches. Their effectiveness was limited, however, by several factors that inhibit participation by women with physical disabilities. One recent study identified four major barriers to participation in a health promotion program by women with

physical disabilities: transportation, cost of program, lack of energy, and lack of knowledge concerning program availability. When these barriers were eliminated by providing free transportation, charging no fee for the program, reducing the fatigue that often occurs getting to a site by providing door-to-door transportation, and developing an accessible and individually-designed exercise program at a fitness center, attendance in the program was over 85 percent and every participant completed the program.⁵

Recent qualitative studies of health promotion efforts among Deaf women highlight the need to address the barriers specific to the type and/or severity of the disability.^{11, 12} These two studies report that even a group of Deaf women with fairly high levels of education had an alarming lack of knowledge about the meaning or value of standard health screenings, the purposes of prescribed medications such as hormone therapy, or the necessity for other medical or surgical interventions such as hysterectomies.¹² Since prevention strategies are contingent upon knowledge and education, improving health communication to women with disabilities is a requisite first step.

Incidence

There is scant data on the incidence of breast cancer among women with disabilities. Prevalence data from the 2005 California Health Interview Survey indicate that California women with broadly defined disabilities are much more likely than their non-disabled counterparts ever to have been diagnosed with breast cancer (4.4 versus 1.9 percent), but that these differences can be accounted for by the older age distribution of

the sample with disabilities.³¹ Similar prevalence rates do not necessarily imply similar incidence, however, because survival rates may also vary.

As for specific disability groups, the little information that is available is almost entirely for blind women, for whom the reported incidence of breast cancer is lower than in the sighted population.³²⁻³⁵ The reduced risk of breast cancer among blind women appears to be limited to those with total blindness or severe visual impairments,^{32, 35} although one study reported reduced risks across most categories of visual impairment and a decreasing trend with greater level of impairment.³⁴ Generally, the results from these studies are consistent with a hypothesized reduced risk of breast cancer in blind women due to higher levels of melatonin secretion by the pineal gland in response to the lack of ocular light perception.²⁰ These studies, however, tend to be limited by small sample size and lack of information on other breast cancer risk factors that may co-vary with visual impairment. Information on nulliparity, a well-established risk factor for breast cancer, available from one study, suggested that blind women are much more likely to be nulliparous than sighted women.³⁵ This would increase, not decrease, breast cancer risk. Future incidence studies of breast cancer among blind women would be strengthened by incorporation of measured levels of circulating melatonin, greater sample sizes, and information on age at onset of visual impairment and on other breast cancer risk factors.

Beyond the incidence literature among blind women, there is virtually no information concerning the incidence of breast cancer among

other groups of women with disabilities. While a 1998 analysis of the Iowa 65+ Rural Health Study reported a decreased risk of breast cancer among women with disabilities,³⁶ a follow-up study using data from the Longitudinal Study on Aging failed to replicate these findings.³⁷ There is some limited information available on cancer incidence among people with developmental disabilities in Scandinavia. These studies suggest that while the overall incidence rate of cancer in people with developmental disabilities may be similar to that of the general population, the pattern of malignancies appears to be different.^{3,38} A small study in Finland reported no difference in breast cancer incidence among a cohort of people with developmental disabilities, compared to the general population, although this result was based on only 23 cases and included both men and women.³

Observational studies have suggested that the distribution of many of the known breast cancer risk factors is different among people with disabilities, compared to the general population (see Etiology subsection below). This suggests that breast cancer incidence is likely to be different among people with disabilities, compared to those without disabilities. There is a clear need to better document the incidence of breast cancer among people with disabilities. Studies designed to do so should be specific as to type, severity, and age at onset of disability. Results from such studies could help prioritize and target breast cancer prevention efforts among this population.

Etiology

For women with physical limitations, the etiology of breast cancer stems from biologic factors,

combined with increased risk on the array of health conditions and behavioral factors that are associated with breast cancer. Associated sociodemographic characteristics and health behaviors among disabled persons have received a fair degree of attention, although results have not been entirely consistent and studies often have failed to take into account the type and severity of disability.

According to the American Cancer Society,³⁹ women have an increased risk of breast cancer if they experienced menarche before age 12, gave birth for the first time after age 30, have never breast-fed, have a history of diabetes or hypertension, use alcohol, use oral contraceptive or hormone replacement therapy, are obese and have a high fat diet, or are physically inactive. Women with disabilities, particularly physical disabilities, are at higher risk of breast cancer on many of these factors. Some types of disability, such as spina bifida, are associated with early menarche.⁴⁰ Many women with physical disabilities have never had children and, therefore, have never breast-fed.⁴¹ Blind women are also more likely to be nulliparous.³⁵ Some studies have suggested greater hormone therapy use among disabled women,⁴²⁻⁴⁴ while one earlier study suggested the opposite.⁴⁵ We also know that there is a disproportionately high prevalence of diabetes, hypertension, obesity, and physical inactivity in the population of women with physical disabilities,^{14,46-48} characteristics that are likely to yield a higher risk of breast cancer.²³ Lower rates of physical activity have also been reported for women who are blind compared to their sighted counterparts.⁴⁹

Although evidence is mixed about the link between smoking and breast cancer, studies have shown that certain segments of the disabled population (including both men and women) are more likely to smoke and be heavier smokers.⁵⁰⁻⁵⁴ However, one study found no differences in tobacco use by disability status.¹⁴ Smoking habits may⁵¹ or may not⁵³ vary by the type and severity of disability. One population-based study found that women with physical disabilities between the ages of 18 and 44 were twice as likely to smoke as women without disabilities in the same age group.⁴⁶ The role of smoking in breast carcinogenesis remains unclear, although recently evidence for a risk relationship has been mounting (see Section I, Chapter A, on Secondhand Smoke).

Better information on the characteristics and health behaviors of women with disabilities, in conjunction with better information on incidence, could provide useful insights into etiology. Disentangling some of the seemingly incongruous findings may help illuminate the importance of competing risks and alternative pathways of breast carcinogenesis. Identifying which risk factors are more prevalent among the various groups of disabled women could provide avenues for targeted breast cancer prevention efforts.

Screening

Comparatively, research on breast cancer screening among women with disabilities has received more attention than other areas of the breast cancer continuum. Most of the literature on this topic to date has focused on mammography utilization. Nearly every study has reported lower rates of screening mammography among women with disabilities compared to women without

disabilities.^{13-15, 17, 46, 55-58} Some studies, however, found this only to be true among women with more severe disabilities^{15-17, 46, 55, 59} or among women with specific types of disabilities, such as developmental disabilities¹⁴ or disabilities involving mobility limitations of the lower extremities.⁵⁹ Furthermore, one study reported that mammography use was less frequent among women with long-term but not short-term disability.¹³

Data from the 2005 California Health Interview Survey show gaps in receipt of mammograms during the prior year between women 40 years of age or older with and without disabilities, differences that are statistically significant when age differences between the two populations are controlled. While 64.7 percent of women without any type of disability reported prior-year mammograms, only 61.3 percent of women with broadly defined disabilities did so. The gap is much larger when a narrower definition of disability is used. For example, only 54.4 percent of those who reported difficulty leaving the home alone had received a mammogram in the prior year, as had 56.3 percent of those reporting difficulty with self-care activities such as bathing and dressing.³¹ Prior analyses of California data also found disparities by disability status.^{60, 61}

Data from the 1998 and 2000 Behavioral Risk Factor Surveillance System (BRFSS) suggest that disparities in mammography use by disability status may be lessening.¹⁵ Data from the 1998 survey showed women with severe disabilities were less likely to receive mammograms, while the 2000 survey suggested women with severe disabilities were slightly more likely to receive

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mammograms than the population without disabilities.¹⁵ No similar changes, however, were seen in the prevalence of clinical breast exams among women with disabilities for the same time period.¹⁵

Identifying barriers to screening in the population with disabilities is the first step to eliminating those barriers. Research to date has identified a number of physical and attitudinal barriers to breast cancer screening. Physical barriers cited include: transportation difficulties; heavy doors; inaccessible offices, bathrooms, exam tables, and mammography equipment; and inadequate time allotment for appointments.^{16, 17, 57, 62-64} A 1999 study reported that nearly 20 percent of primary care physicians surveyed had offices that were not compliant with the ADA and these physicians were unable to serve their patients with disabilities as a result.⁶⁵ Attitudinal and/or informational barriers, both among women with disabilities and their health care providers, also impede breast cancer screening efforts. Health care providers receive very little, if any, training in health promotion efforts for patients with disabilities. Consequently, many are ill equipped to interact with patients with disabilities and are uninformed of their needs. Women with disabilities have reported that healthcare providers often neglect to address screening even after being directly asked^{16, 17} and many cite the ‘negative attitude of health care providers’ as the most difficult barrier to health care access.^{66, 67} For patients with certain disabilities, clinicians may believe that life expectancy is not sufficient to warrant preventive screenings.^{17, 68} Patients with disabilities may believe that they do not need a mammogram because they are at low risk for breast cancer⁶⁸ or

they do not understand the purpose of it. Steinberg and colleagues reported the belief among some Deaf women that mammography is only necessary for women who are experiencing symptoms of breast cancer.¹²

As is true of the other aspects of the breast cancer prevention continuum, barriers to screening are likely to vary by the type and severity of disability. Language barriers may be particularly acute for Deaf women who are often not provided with a qualified sign language interpreter during health care visits.^{11, 12} Many Deaf women, in fact, do not use interpreters and are limited by a knowledge of medical vocabulary similar to that of non-English speaking immigrants.¹² Perceived physical barriers to mammography may pose especially strong barriers for women with severe lower extremity disabilities who incorrectly assume that one must stand for a mammogram or who find that the clinic’s mammography equipment is indeed inaccessible to them.^{13, 17, 62, 64, 68} Many women with disabilities have health conditions requiring a great deal of contact with healthcare providers, and they may be resistant to scheduling additional visits for preventive services; bad experiences during prior attempts at mammography may further dissuade them.^{63, 67, 69}

A small number of projects have attempted to develop education campaigns or interventions aimed at increasing mammography among women with disabilities. These include a CDC-funded public education campaign,⁷⁰ a CDC-funded pilot project testing two interventions targeting women with disabilities in the San Francisco Bay Area,⁷¹ and an ongoing CBCRP-funded project to develop an intervention for Latinas with disabilities living

in California's Central Coast.⁷² The CBCRP-funded Breast Health for Women with Disabilities, in the San Francisco Bay Area, has used telephone survey data to develop a manual with best practices on making breast cancer screening accessible to women with disabilities and to educate disability and breast cancer screening agencies.⁷³

In summary, while disparities in breast cancer screening for women with disabilities are well documented, there remain critical gaps in our knowledge of the factors that underlie these disparities. In order to develop effective and targeted intervention strategies to promote breast cancer screening among women with disabilities, future research must focus on identifying the specific financial, physical, and attitudinal/informational barriers to breast cancer screening, taking into account both the type and severity of disability.

Diagnosis

If disparities in screening exist, as the discussion above suggests, then presumably disparities in stage at diagnosis would exist as well. There is, however, a dearth of evidence to support or deny this supposition. Two studies have suggested that women with disabilities are diagnosed at a later stage than women without disabilities,^{18, 74} while another did not.⁴ The varying ways that disability was defined across these three studies may partially explain the disparate findings. There is evidence that women who are obese tend to be diagnosed at a later stage.^{75, 76} Obesity, however, in the context of disability research is complicated. While obesity can be considered a cause of

disability in and of itself, it also is a frequent consequence of another disability.

Access to Clinical Trials

As a matter of protocol, women with disabilities are usually excluded from participation in clinical trials.⁷⁷ The mere presence of disability or any of its frequent co-morbid conditions are almost always listed as exclusion criteria. The *de facto* exclusion of women with disabilities from clinical trials often results from inaccessibility of the trial facilities or the lack of equipment that can accommodate the needs of women with mobility impairments.⁷⁸ Consequently, no information is available on optimal treatment protocols for women who have a disability.

Treatment

A recent, groundbreaking study found substantial differences in treatment between women with disabilities who were diagnosed with early-stage breast cancer and their non-disabled counterparts. In a large study using registry data from several geographical areas in the U.S., women under age 65 who qualified for Social Security Disability Insurance (SSDI) and Medicare coverage were found to be much less likely to have received breast conserving surgery (as opposed to mastectomy) than similar women who were not on SSDI or Medicare.¹⁹ The researchers were unable to determine the extent to which these differences were attributable to patient preference versus physician recommendation.

Previous studies were much less definitive. Caban and colleagues studied treatment in a small cohort of women undergoing surgery for breast cancer

(n = 234 women, 39 of whom had disabilities). In this study, in which disability was defined as ‘having a physical disability that interfered with mobility or activities of daily living,’ lower rates of breast conserving surgery and neoadjuvant chemotherapy were found, although they were not statistically significant.⁴ Recently, results from a study of patients with Alzheimer’s disease suggested dramatically different treatment protocols for this set of patients.⁷⁴ Women with Alzheimer’s disease were less likely than those without the disease to receive surgery, radiation, and chemotherapy for their breast cancer.⁷⁴ Reasons for these disparities were unclear.

More information on breast cancer treatment received by women with disabilities clearly is needed to identify potential disparities in breast cancer treatment by disability status. Furthermore, it is important to identify and distinguish between differences that are necessitated by the disability itself, versus disparities that are a consequence of misinformation and/or discrimination. For example, the inability to lie flat or adequately abduct the arm (as is common with some types of physical disabilities) may make it difficult or impossible to deliver radiation therapy⁴ and consequently would preclude breast conserving surgery as well. Likewise, there have been reports of severe side effects of radiation therapy when administered to women with active lupus.⁴ Unfortunately, such observations are often anecdotal and undocumented.

There is no information on how breast cancer treatment affects a woman’s disability-related functional limitations. Women who rely on their arms for transferring and conducting their daily

activities or who use crutches for ambulation would have a severe reduction in functioning after surgery and while recovering. How they manage to meet their functional needs during recovery is unknown. No studies have examined whether their rehabilitation needs are met. How chemotherapy or radiation therapy affect their functioning is unknown. It is also unknown whether they are ever able to achieve their pre-breast-cancer-treatment level of functioning. There is no documentation about how the course of their recovery from breast cancer differs compared to women with no preexisting disabilities. The exclusion of women from clinical trials and from health research in general has created a void of information on how the presence of a disability should or should not influence therapeutic treatment modalities.

Survival

There are some characteristics that are more prevalent in people with disabilities (e.g. poverty, smoking, depression, stress, social isolation, publicly insured, obesity) that could negatively impact survival. Furthermore, treatment differences (see above) may also affect survival among women with disabilities. More study is clearly warranted.

Co-Morbidity

There have been no systematic studies of overlap between cancer co-morbidities and disability co-morbidities. Previous research has identified pain, weakness, and fatigue as the most common co-morbid or secondary conditions reported by women with physical disabilities.⁴⁸ Other common problems that often accompany disability

are overweight,^{48, 79} depression,^{80, 81} and mobility limitations.⁸⁰ Each of these six conditions could also be a consequence of breast cancer treatment and recovery. The fatigue and weakness that result from radiation therapy would likely compound pre-diagnosis fatigue and weakness. No studies, however, have examined levels of these conditions prior to cancer diagnosis compared to post treatment. Breast surgery often results in temporary or permanent limitations in the use of the arm on the affected side. If this arm is needed for propelling a wheelchair or crutch use, its impairment could result in additional mobility limitations. Many women take steroids to manage the inflammation that is part of joint and connective tissue diseases and must deal with the side effect of weight problems. If steroids are then needed as part of breast cancer treatment, it is not known whether weight problems will increase or if the pre-morbid dietary coping behaviors will serve to minimize the effect of additional medication. Similarly, coping behaviors for depression associated with disability may transfer to dealing with the diagnosis of cancer. On the other hand, being confronted with two stigmatizing and life-altering conditions simultaneously may exceed some women's coping capacity and lead to increased needs for psychotherapy and antidepressive medication. In many cases, it is impossible to separate the effect of disabilities from the effect of cancer treatment on these co-morbid conditions. Studies that compare the status of these conditions pre-diagnosis with post-treatment would offer valuable information.

Quality of Life

Quality of life after breast cancer for women with disabilities may be influenced by factors that go beyond those experienced by women in general. These factors include: 1) the quality of treatment for the minimization of complications; 2) attentiveness of medical personnel to disability-related functional needs that may be heightened due to breast cancer treatment; 3) the willingness of family and other assistance resources to compensate for temporarily impaired functioning; 4) the availability of assistive devices to compensate for temporarily impaired functioning; 5) care by medical personnel who are knowledgeable in the treatment of pain, fatigue, weakness, and other secondary conditions commonly reported by women with disabilities; and 6) the availability of individual peer support and support groups that are accessible, knowledgeable, and sensitive to the emotional and physical needs of women with disabilities who are recovering from breast cancer.

Mortality

There appears to be only a single study on breast cancer survival among women with disabilities, the same study that found differential treatment rates. Working-age women with disabilities who had been diagnosed with early-stage breast cancer were found to have higher all-cause and breast-cancer-specific mortality rates than women without disabilities, even after stratifying by stage of diagnosis and adjusting for other factors.¹⁹ It is not clear whether differential mortality rates are related to differences in treatment or to other disability-related factors.

Beyond the one study, virtually nothing is known about breast cancer mortality among women with disabilities. Presumably the lower rates of screening among women with disabilities (as discussed above) would translate to higher mortality rates, but there is currently little evidence to support this. A study of Social Security Disability Insurance (SSDI)-qualifying women reported that those with disabilities had higher all-cause mortality rates than non-SSDI-qualifying women, but similar breast-cancer-specific mortality, despite being diagnosed at a later stage.¹⁸

In the first study to evaluate cause-specific mortality among people with cerebral palsy (CP), it was reported that women with CP were three-times more likely to die from breast cancer than comparable women in the general population.⁸² Since this was a mortality linkage study, the investigators were unable to evaluate the degree to which the excess breast cancer mortality was a reflection of differences in staging and treatment versus differences in incidence. The authors suggest that these findings may be partially explained by the high prevalence of nulliparity among women with CP, but argue this is unlikely to fully explain the three-fold increase in mortality.⁸² These findings are alarming and certainly warrant more in-depth investigation. Linkage mortality studies such as this one that make use of preexisting databases are relatively inexpensive and quick to perform. They provide a valuable tool for identifying disparities among segments of the population and determining areas of more focused research.

Conclusions and Future Directions

Despite the large and growing number of women with disabilities in the U.S., there is a paucity of information on the burden of breast cancer among these women. Given that women with disabilities constitute one of the most economically disadvantaged populations living in this country (an estimated 26 percent of California women with severe disabilities live in poverty),³¹ large disparities in breast cancer are likely to exist. The limited data we have to date suggest that women with disabilities face higher risk, are less likely to be screened, are more likely to be diagnosed at a later stage, are less likely to receive breast-conserving surgery compared to mastectomy, and may be ultimately at greater risk from dying of breast cancer than their non-disabled counterparts. Conspicuous by its absence is any information about whether their specific disability-related needs are met or even addressed in the processes associated with breast cancer diagnosis, treatment, and recovery. These conclusions, however, are based on very sparse data and may be limited to certain types and/or levels of disability. In order to eliminate potential disparities in breast cancer associated with disability status, we must first identify who is most at risk for such disparities and elucidate the factors that contribute to them.

Comprehensive studies are needed to understand the breast cancer-related experiences of women with a broad spectrum of disabilities, from risk factors to screening to treatment to recovery to long-term survival and quality of life. Research must focus not only on the extent that such women, viewed as a minority group, face increased risk, greater prevalence, and disparities

in treatment methods and survival rates, but also on the specific barriers to prevention, screening, and treatment experienced by subgroups within the disability community, and on strategies for overcoming such barriers.

For example, to what extent do information and communication barriers prevent Deaf women or women with cognitive disabilities from seeking and obtaining preventive screenings, or from obtaining optimal treatments? How does the physical inactivity of many women with mobility limitations affect their breast cancer incidence, and what can be done to reduce their risk? To what extent do inaccessible facilities and equipment prevent women with physical disabilities from gaining access to preventive services, breast cancer screenings, and treatment? What is the interaction between a preexisting disability, along with secondary conditions often associated with that disability, and additional functional limitations caused by the cancer and/or its treatment? How do women with mental health disabilities, or mental health issues secondary to some other primary disability, cope differently with issues related to screening, treatment, recovery, and survival?

Clinical practice guidelines are needed to ensure that the specific functional concerns and complex, multifaceted life situation of women with physical, sensory, and intellectual disabilities are considered in the development of breast cancer treatment plans. Concurrently, education and awareness campaigns are needed that focus on women with disabilities and their families to increase their interest in and pursuit of cancer screening, to empower them to be equal partners in the

development of their treatment plans, and to encourage them to demand the highest quality cancer care services that address their disability-related needs, enable them to maintain their level of functioning, minimize complications during recovery, and maximize their chances for survival.

Research shedding light on these and related issues has the potential to substantially reduce breast cancer risks and disparities in screening, treatment, recovery, and survival, thereby lessening the burden of breast cancer for women with all types of disabilities.

References

1. United States Bureau of the Census, American FactFinder. Table B18002: Sex by Age by Disability Status for the Civilian Noninstitutionalized Population 5 Years and Over - California. In: United States Bureau of the Census. 2005 American Community Survey Data Set. Washington, DC, USA: United States Bureau of the Census, American FactFinder, 2005. Available at http://factfinder.census.gov/servlet/DTable?_bm=y&-state=dt&-context=dt&-ds_name=ACS_2005_EST_G00_&-mt_name=ACS_2005_EST_G2000_B18002&-tree_id=305&-_caller=geoselect&-geo_id=04000US06&-search_results=01000US&-format=&-_lang=en.
2. United States Bureau of the Census, American FactFinder. Table PCT17: Group Quarters Population by Sex by Age by Group Quarters Type - California. In: United States Bureau of the Census. Census 2000 Summary File (SF 1) 100-Percent Data Set. Washington, DC, USA: United States Bureau of the Census, American FactFinder, 2000. Available at http://factfinder.census.gov/servlet/DTable?_bm=y&-state=dt&-context=dt&-ds_name=DEC_2000_SF1_U&-mt_name=DEC_2000_SF1_U_PCT017&-tree_id=305&-redoLog=true&-_caller=geoselect&-geo_id=04000US06&-geo_id=NBSP&-search_results=01000US&-format=&-_lang=en.
3. Patja K, Eero P, Iivanainen M. Cancer incidence among people with intellectual disability. *J Intellect Disabil Res.* 2001, 45(Pt 4):300-7.
4. Caban ME, Nosek MA, Graves D, Esteva FJ, McNeese M. Breast carcinoma treatment received by women with disabilities compared with women without disabilities. *Cancer.* 2002, 94(5):1391-6.
5. Rimmer JH. Health promotion for people with disabilities: the emerging paradigm shift from disability prevention to prevention of secondary conditions. *Phys Ther.* 1999, 79(5):495-502.
6. United States Department of Health and Human Services (DHHS). *Healthy People 2000: National Health Promotion and Disease Prevention Objectives.* Washington, DC, USA: United States Department of Health and Human Services (DHHS), 1991. Report ID: DHHS (PHS) 91-50213.

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7. United States Department of Health and Human Services (DHHS). *Healthy People 2010: Understanding and Improving Health and Objectives for Improving Health* (2 vols.). 2nd ed. Washington, DC, USA: United States Department of Health and Human Services (DHHS), 2000. Report ID: S/N 017-001-00547-9. Available at <http://www.health.gov/healthypeople/>.
8. Wang Q. *Disability and American Families: 2000* (Census 2000 Special Reports). Washington, DC, USA: United States Bureau of the Census, 2005. Report ID: CENSR-23. Available at <http://www.census.gov/prod/2005pubs/censr-23.pdf>.
9. Iezzoni LI. Using administrative data to study persons with disabilities. *Milbank Q.* 2002, 80(2):347-79.
10. World Health Organization (WHO). *International Classification of Functioning, Disability and Health (ICF)* [web page]. Geneva, Switzerland: World Health Organization (WHO), 2006. Available at <http://www3.who.int/icf/icftemplate.cfm>. Accessed 26 Sep 2006.
11. Sadler GR, Gunsauls DC, Huang J, Padden C, Elion L, Galey T, Brauer B, Ko CM. Bringing breast cancer education to deaf women. *J Cancer Educ.* 2001, 16(4):225-8.
12. Steinberg AG, Wiggins EA, Barmada CH, Sullivan VJ. Deaf women: experiences and perceptions of healthcare system access. *Womens Health (Larchmt).* 2002, 11(8):729-41.
13. Schootman M, Jeffe DB. Identifying factors associated with disability-related differences in breast cancer screening (United States). *Cancer Causes Control.* 2003, 14(2):97-107.
14. Havercamp SM, Scandlin D, Roth M. Health disparities among adults with developmental disabilities, adults with other disabilities, and adults not reporting disability in North Carolina. *Public Health Rep.* 2004, 119(4):418-26.
15. Diab ME, Johnston MV. Relationships between level of disability and receipt of preventive health services. *Arch Phys Med Rehabil.* 2004, 85(5):749-57.

Identifying Gaps in Breast Cancer Research

16. Nosek MA, Howland CA. Breast and cervical cancer screening among women with physical disabilities. *Arch Phys Med Rehabil.* 1997, 78(12 Suppl 5):S39-44.
17. Smeltzer SC. Preventive health screening for breast and cervical cancer and osteoporosis in women with physical disabilities. *Fam Community Health.* 2006, 29(1 Suppl):35S-43S.
18. Roetzheim RG, Chirikos TN. Breast cancer detection and outcomes in a disability beneficiary population. *J Health Care Poor Underserved.* 2002, 13(4):461-76.
19. McCarthy EP, Ngo LH, Roetzheim RG, Chirikos TN, Li D, Drews RE, Iezzoni LI. Disparities in breast cancer treatment and survival for women with disabilities. *Ann Intern Med.* 2006, 145(9):637-45.
20. Coleman MP, Reiter RJ. Breast cancer, blindness and melatonin. *Eur J Cancer.* 1992, 28(2-3):501-3.
21. Bao T, Prowell T, Stearns V. Chemoprevention of breast cancer: tamoxifen, raloxifene, and beyond. *Am J Ther.* 2006, 13(4):337-48.
22. Uyei A, Peterson SK, Erlichman J, Broglio K, Yekell S, Schmeler K, Lu K, Meric-Bernstam F, Amos C, Strong L, Arun B. Association between clinical characteristics and risk-reduction interventions in women who underwent BRCA1 and BRCA2 testing: a single-institution study. *Cancer.* 2006, 107(12):2745-51.
23. Willett WC, Rockhill B, Hankinson SE, Hunter D, Golditz GA. Nongenetic Factors in the Causation of Breast Cancer. In: Harris JR, Lippman ME, Morrow M, Osborne CK, editors. *Diseases of the Breast.* 3rd ed. Philadelphia, PA, USA: Lippincott Williams & Wilkins, 2004. (ISBN: 07-8174-619-1)
24. Froehlich-Grobe K, White GW. Promoting physical activity among women with mobility impairments: a randomized controlled trial to assess a home- and community-based intervention. *Arch Phys Med Rehabil.* 2004, 85(4):640-8.

California Breast Cancer Research Program

25. Harrison T. Health promotion for persons with disabilities: what does the literature reveal? *Fam Community Health*. 2006, 29(1 Suppl):12S-9S.
26. Hughes RB. Achieving effective health promotion for women with disabilities. *Fam Community Health*. 2006, 29(1 Suppl):44S-51S.
27. Rimmer JH, Silverman K, Braunschweig C, Quinn L, Liu Y. Feasibility of a health promotion intervention for a group of predominantly African American women with type 2 diabetes. *Diabetes Educ*. 2002, 28(4):571-80.
28. Stuifbergen A, Becker H, Rogers S, Timmerman G, Kullberg V. Promoting wellness for women with multiple sclerosis. *J Neurosci Nurs*. 1999, 31(2):73-9.
29. Stuifbergen AK, Becker H, Blozis S, Timmerman G, Kullberg V. A randomized clinical trial of a wellness intervention for women with multiple sclerosis. *Arch Phys Med Rehabil*. 2003, 84(4):467-76.
30. Stuifbergen AK, Harrison TC, Becker H, Carter P. Adaptation of a wellness intervention for women with chronic disabling conditions. *J Holist Nurs*. 2004, 22(1):12-31.
31. Kaye SH. Unpublished tabulations from the 2005 California Health Interview Survey. 2007.
32. Hahn RA. Profound bilateral blindness and the incidence of breast cancer. *Epidemiology*. 1991, 2(3):208-10.
33. Feychting M, Osterlund B, Ahlbom A. Reduced cancer incidence among the blind. *Epidemiology*. 1998, 9(5):490-4.
34. Verkasalo PK, Pukkala E, Stevens RG, Ojamo M, Rudanko SL. Inverse association between breast cancer incidence and degree of visual impairment in Finland. *Br J Cancer*. 1999, 80(9):1459-60.
35. Kliukiene J, Tynes T, Andersen A. Risk of breast cancer among Norwegian women with visual impairment. *Br J Cancer*. 2001, 84(3):397-9.

Identifying Gaps in Breast Cancer Research

36. Cerhan JR, Chiu BC-H, Wallace RB, Lemke JH, Lynch CF, Torner JC , Rubenstein LM. Physical activity, physical function, and the risk of breast cancer in a prospective study among elderly women. *J Gerontol A Biol Sci Med Sci.* 1998, 53:M351-6.
37. Wyrwich KW, Wolinsky FD. Physical activity, disability, and the risk of hospitalization for breast cancer among older women. *J Gerontol A Biol Sci Med Sci.* 2000, 55(7):M418-21.
38. Cooke LB. Cancer and learning disability. *J Intellect Disabil Res.* 1997, 41 (Pt 4):312-6.
39. American Cancer Society (ACS). Cancer Reference Information: Detailed Guide: Breast Cancer: What Are the Risk Factors for Breast Cancer? [web page]. Atlanta, GA, USA: American Cancer Society (ACS), 2007. Available at http://www.cancer.org/docroot/CRI/content/CRI_2_4_2X_What_are_the_risk_factors_for_breast_cancer_5.a.sp. Accessed 26 Mar 2007.
40. Furman L, Mortimer JC. Menarche and menstrual function in patients with myelomeningocele. *Dev Med Child Neurol.* 1994, 36(10):910-7.
41. Nosek MA, Howland C, Rintala DH, Young ME, Chanpong GF. National Study of Women with Physical Disabilities: Final Report. *Sexuality and Disability.* 2001, 19(1):5-39.
42. Becker H, Stuijbergen AK, Gordon D. The decision to take hormone replacement therapy among women with disabilities. *West J Nurs Res.* 2002, 24(3):264-81.
43. Becker H, Stuijbergen AK, Gordon D. Menopausal experiences and hormone replacement therapy use among women with physical impairments. *Womens Health Issues.* 2002, 12(4):212-9.
44. Kalpakjian CZ, Riley BB, Quint EH, Tate DG. Hormone replacement therapy and health behavior in postmenopausal polio survivors. *Maturitas.* 2004, 48(4):398-410.

California Breast Cancer Research Program

45. Jackson AB, Wadley V. A multicenter study of women's self-reported reproductive health after spinal cord injury. *Arch Phys Med Rehabil.* 1999, 80(11):1420-8.
46. Chevarley FM, Thierry JM, Gill CJ, Ryerson AB, Nosek MA. Health, preventive health care, and health care access among women with disabilities in the 1994-1995 National Health Interview Survey, Supplement on Disability. *Womens Health Issues.* 2006, 16(6):297-312.
47. Stuifbergen AK. Building health promotion interventions for persons with chronic disabling conditions. *Fam Community Health.* 2006, 29(1 Suppl):28S-34S.
48. Nosek MA, Hughes RB, Petersen NJ, Taylor HB, Robinson-Whelen S, Byrne M, Morgan R. Secondary conditions in a community-based sample of women with physical disabilities over a 1-year period. *Arch Phys Med Rehabil.* 2006, 87(3):320-7.
49. Pukkala E, Verkasalo PK, Ojamo M, Rudanko SL. Visual impairment and cancer: a population-based cohort study in Finland. *Cancer Causes Control.* 1999, 10(1):13-20.
50. Jones GC, Bell K. Adverse health behaviors and chronic conditions in working-age women with disabilities. *Fam Community Health.* 2004, 27(1):22-36.
51. Brawarsky P, Brooks DR, Wilber N, Gertz RE Jr, Klein Walker D. Tobacco use among adults with disabilities in Massachusetts. *Tob Control.* 2002, 11(Suppl 2):ii29-33.
52. Blum RW, Kelly A, Ireland M. Health-risk behaviors and protective factors among adolescents with mobility impairments and learning and emotional disabilities. *J Adolesc Health.* 2001, 28(6):481-90.
53. Hollar D. Risk behaviors for varying categories of disability in NELS:88. *J Sch Health.* 2005, 75(9):350-8.
54. Mitra M, Wilber N, Allen D, Walker DK. Prevalence and correlates of depression as a secondary condition among adults with disabilities. *Am J Orthopsychiatry.* 2005, 75(1):76-85.

Identifying Gaps in Breast Cancer Research

55. Chan L, Doctor JN, MacLehose RF, Lawson H, Rosenblatt RA, Baldwin LM, Jha A. Do Medicare patients with disabilities receive preventive services? A population-based study. *Arch Phys Med Rehabil.* 1999, 80(6):642-6.
56. Iezzoni LI, McCarthy EP, Davis RB, Siebens H. Mobility impairments and use of screening and preventive services. *Am J Public Health.* 2000, 90(6):955-61.
57. Schootman M, Fuortes LJ. Breast and cervical carcinoma: the correlation of activity limitations and rurality with screening, disease incidence, and mortality. *Cancer.* 1999, 86(6):1087-94.
58. Wei W, Findley PA, Sambamoorthi U. Disability and receipt of clinical preventive services among women. *Womens Health Issues.* 2006, 16(6):286-96.
59. Iezzoni LI, McCarthy EP, Davis RB, Harris-David L, O'Day B. Use of screening and preventive services among women with disabilities. *Am J Med Qual.* 2001, 16(4):135-44.
60. King G. Breast cancer screening among women with disabilities: data from the California Behavioral Risk Factor Survey 2002. In: EPICgram. Report No. 8Sacramento, CA, USA: California Department of Health Services, Epidemiology and Prevention for Injury Control (EPIC) Branch, 2004 Sep. Available at http://www.dhs.ca.gov/epic/publications/EPICgrams/EG8/EPICgram8_%20BRFSMammogram.pdf.
61. Ramirez A, Farmer GC, Grant D, Papachristou T. Disability and preventive cancer screening: results from the 2001 California Health Interview Survey. *Am J Public Health.* 2005, 95(11):2057-64.
62. Graham A, Savic G, Gardner B. Cervical and breast cancer screening in wheelchair dependent females. *Spinal Cord.* 1998, 36(5):340-4.
63. Mele N, Archer J, Pusch BD. Access to breast cancer screening services for women with disabilities. *J Obstet Gynecol Neonatal Nurs.* 2005, 34(4):453-64.

California Breast Cancer Research Program

64. Welner SL. Screening issues in gynecologic malignancies for women with disabilities: critical considerations. *J Womens Health*. 1998, 7(3):281-5.
65. Grabois EW, Nosek MA, Rossi CD. Accessibility of primary care physicians' offices for people with disabilities. An analysis of compliance with the Americans with Disabilities Act. *Arch Fam Med*. 1999, 8(1):44-51.
66. Schopp LH, Kirkpatrick HA, Sanford TC, Hagglund KJ, Wongvatunyu S. Impact of comprehensive gynecologic services on health maintenance behaviours among women with spinal cord injury. *Disabil Rehabil*. 2002, 24(17):899-903.
67. Thierry JM. Increasing breast and cervical cancer screening among women with disabilities. *J Womens Health Gend Based Med*. 2000, 9(1):9-12.
68. Schopp LH, Sanford TC, Hagglund KJ, Gay JW, Coatney MA. Removing service barriers for women with physical disabilities: promoting accessibility in the gynecologic care setting. *J Midwifery Womens Health*. 2002, 47(2):74-9.
69. Thierry JM. Barriers to breast cancer screening among women aged 40 years and older who have physical disabilities [conference proceeding]. Presented at the American Public Health Association (APHA), 133rd Annual Meeting & Exposition; Philadelphia, PA, USA. Washington, DC, USA: American Public Health Association (APHA), 2005. Available at http://apha.confex.com/apha/133am/techprogram/paper_105752.htm.
70. Thierry JM. Developing concepts, messages, and health promotion materials to increase breast cancer awareness among women with physical disabilities [conference proceeding]. Presented at the American Public Health Association (APHA), 133rd Annual Meeting & Exposition; Philadelphia, PA, USA. Washington, DC, USA: American Public Health Association (APHA), 2005. Available at http://apha.confex.com/apha/133am/techprogram/paper_114307.htm.

Identifying Gaps in Breast Cancer Research

71. Hoban RE. Healthy Women Project: A multifaceted intervention for improving screenings for breast and cervical cancer among women with physical disabilities [conference proceeding]. Presented at the American Public Health Association (APHA), 134th Annual Meeting & Exposition; Boston, MA, USA. Washington, DC, USA: American Public Health Association (APHA), 2006. Available at http://apha.confex.com/apha/134am/techprogram/paper_133252.htm.
72. Kaye HS, Quezada E, Investigators. Increasing mammography among latinias with disabilities (Grant No. 12AB-2700). In: Univeristy of California, Office of the President, California Breast Cancer Research Program. Research Portfolio. Oakland, CA, USA: California Breast Cancer Research Program, 2007. Available at http://www.cbcrp.org/research/PageGrant.asp?grant_id=4760.
73. D'Onofrio C, Cupolo-Freeman A, Investigators. Increasing breast health access for women with disabilities (Grant No. 4BB-2400). In: Univeristy of California, Office of the President, California Breast Cancer Research Program. Research Portfolio. Oakland, CA, USA: California Breast Cancer Research Program, 2007. Available at http://www.cbcrp.org/research/PageGrant.asp?grant_id=225.
74. Gorin SS, Heck JE, Albert S, Hershman D. Treatment for breast cancer in patients with Alzheimer's disease. *J Am Geriatr Soc*. 2005, 53(11):1897-904.
75. Wee CC, McCarthy EP, Davis RB, Phillips RS. Screening for cervical and breast cancer: is obesity an unrecognized barrier to preventive care? *Ann Intern Med*. 2000, 132(9):697-704.
76. Fontaine KR, Heo M, Allison DB. Body weight and cancer screening among women. *J Womens Health Gen Based Med*. 2001, 10(5):463-70.
77. Iezzoni LI. Targeting health care improvement for persons with disabilities. *Int J Qual Health Care*. 2003, 15(4):279-81.

California Breast Cancer Research Program

78. Nosek, M. A. and Simmons, D. K. People with Disabilities as a Health Disparities Population: The Case of Sexual and Reproductive Health Disparities. *California Journal of Health Promotion* . 2007, in press.
79. Kinne S, Patrick DL, Doyle DL. Prevalence of secondary conditions among people with disabilities. *Am J Public Health*. 2004, 94(3):443-5.
80. Coyle CP, Santiago MC, Shank JW, Ma GX, Boyd R. Secondary conditions and women with physical disabilities: a descriptive study. *Arch Phys Med Rehabil*. 2000, 81(10):1380-7.
81. Hughes RB, Robinson-Whelen S, Taylor HB, Petersen NJ, Nosek MA. Characteristics of depressed and nondepressed women with physical disabilities. *Arch Phys Med Rehabil*. 2005, 86(3):473-9.
82. Strauss D, Cable W, Shavelle R. Causes of excess mortality in cerebral palsy. *Dev Med Child Neurol*. 1999, 41(9):580-5.