



Disparities

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5.1 Introduction

Health disparity populations within the United States (USA) have been defined by the National Institute on Minority Health and Health Disparities as including racial/ethnic minorities; low socioeconomic status; rural, sexual, and gender minority; and groups with other fundamental characteristics (e.g., disability and geographic region). Factors that influence health disparities occur across a continuum of multi-level drivers including biological, behavioral, physical built, sociocultural environment and health systems. Cancer health disparities, as defined by the

National Cancer Institute's Center to Reduce Cancer Health Disparities, are "adverse differences in cancer incidence (new cases), cancer prevalence (all existing cases), cancer death (mortality), cancer survivorship, and burden of cancer or related health conditions that exist among specific population groups in the United States" [1].

Over the past 10 years, we have seen increased interest in disparities in cancer survivorship. The American Society of Clinical Oncology's statement on achieving high-quality cancer survivorship care [2] describes the following limitations in cancer survivorship care as drivers of disparities: (1) lack of standardized models of care, (2) paucity of clinical guidance for survivors of various cancer types treated across the life span, and (3) barriers to access to high-quality survivorship care (e.g., lack of insurance, insurance restrictions). This report endorsed the need for investments in research to expand the evidence base to enhance the quality of cancer survivorship care provided in clinical practices [2, 3]. We have seen significant expansion in the knowledge base. It has moved beyond early epidemiological studies focused on elucidating Black-White differences in survival and impact of low socioeconomic status on survival. Now, the literature is informed by numerous studies that examine not only survival but also prevalence and the interface of factors that contribute to ongoing cancer survivorship disparities post-acute treatment for multiple groups (e.g., racial and ethnic minorities, low

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socioeconomic status, individuals with multi-morbidity, and sexual identity). This chapter describes the key research, healthcare, and policy findings related to the intersection of cancer health disparities and cancer survivorship care [4]. Further, the purpose of this chapter is to provide an overview of cancer survivorship disparities focused on key health disparity populations (i.e., racial and ethnic minorities, low socioeconomic status, individuals with multi-morbidity, and sexual identity) as well as the impact of limited access to continuous care and fragmented care systems on cancer survivorship disparities.

5.2 Overview of Disparities in Cancer Outcomes

5.2.1 African-Americans

Differences in cancer survival in the United States continue to persist between non-Hispanic Whites (NHW) and racial ethnic minorities [5, 6]. The burden of cancer has been disproportionately borne by African-Americans, a population with the highest mortality rates and shortest survival times for most cancers [7] compared to all racial and ethnic groups [6, 7]. The diversity of subgroups within the African-American population continues to be understudied despite recent reports that indicate that the demography has shifted with a growing immigrant population more prominent than in previous decades (e.g., 8.7% of the nation's Black population) [8]. Evidence supports that the greatest predictors of health disparities among African-Americans are social (e.g., education, structural racism, income disparities) rather than biological [4, 7]. Five year relative survival is lower among African American breast cancer patients when compared to NHW patients at each stage of diagnosis [5]. Compared to NHW American males, African-American males have 12% higher incidence rates for all cancers combined (e.g., prostate, lung, colorectal, kidney, and pancreas, Fig. 5.1), whereas African-American women are estimated to have a 6%

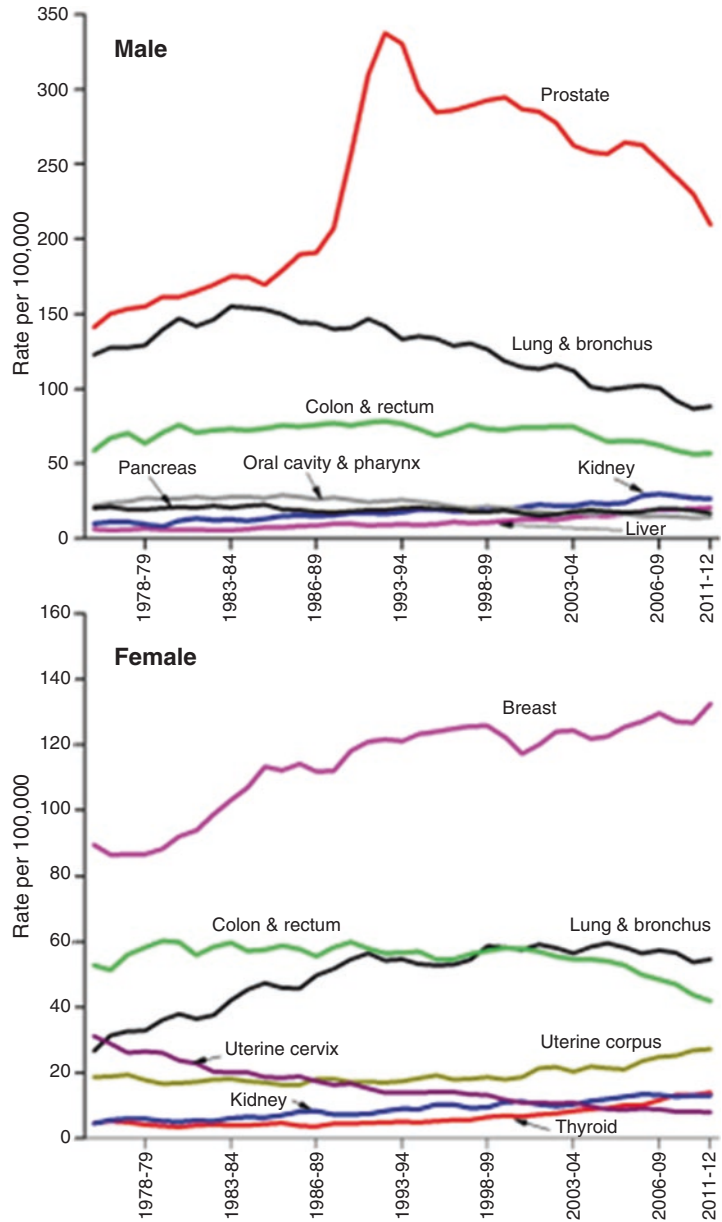
lower incidence rate of all cancers combined compared to NHW American women [6].

Mortality rates for most cancers are higher among African-Americans than NHWs [6]. While the disparity gap has narrowed for most cancers among both men and women, for select cancers, the gap has widened or remained stable [6]. Specifically, the mortality rates for breast cancers have widened between African-American and NHW American women, while the rates have remained stable for colorectal cancer in African-American and NHW American men [6]. Given these trends, a continued emphasis on prevention, early detection, and access to high-quality treatment remains a promising avenue to address health disparities between African-Americans and NHW Americans [6]. Emerging survivorship studies of health service use and neighborhood contextual factors among African-American breast cancer survivors suggest that multilevel strategies that extend beyond the acute phase of care are warranted. One study found that adherence to routine follow-up guideline-recommended surveillance care (e.g., mammography and clinic visits) was poorer among African-American breast cancer survivors when compared to NHW survivors [9]. Further, in a study of ethnic minorities that included a large subsample of African-American survivors, greater neighborhood stress was found to be associated with poorer self-reported health, more comorbid illnesses, and more depressive and higher psychological difficulties [10]. Attending to the morbidity burden and sociocultural contextual factors during the post-acute treatment phase is an emerging area of study. Examining the impact of processes of care and context of care on African-American health disparities is needed, specifically those that extend this growing body of research into examination of other cancer sites.

5.2.2 Hispanic/Latino Americans

In the United States, the Hispanic/Latino population is a heterogeneous ethnic categorization that refers to individuals of Mexican, Cuban, Puerto Rican, South or Central American, Dominican, or

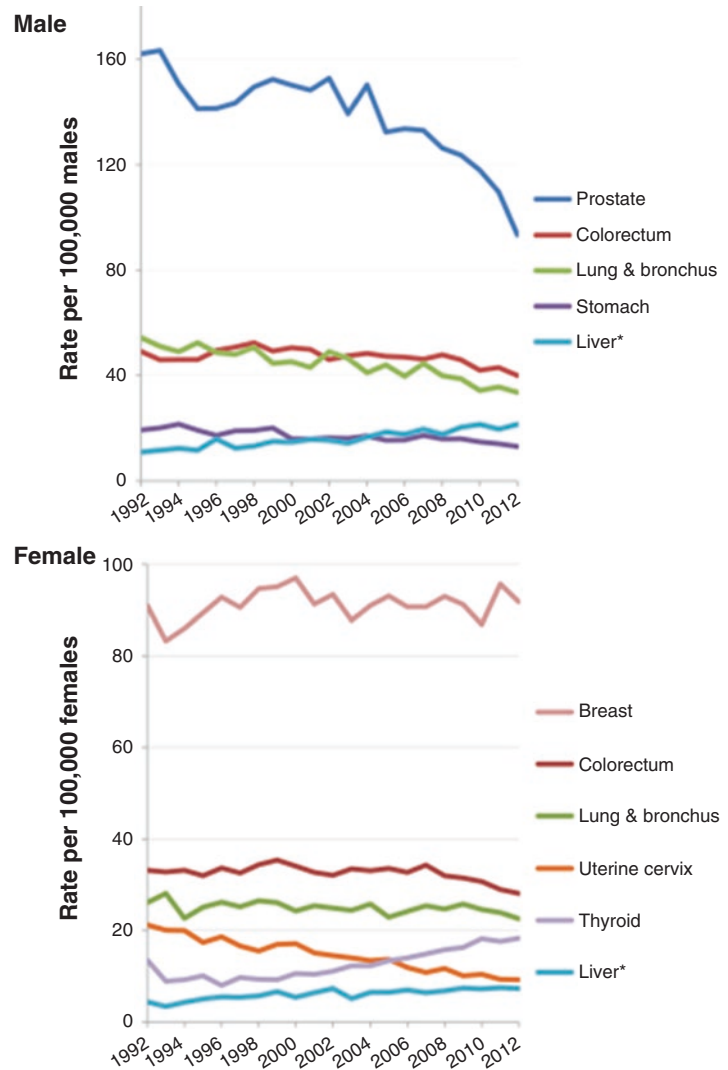
Fig. 5.1 Cancer statistics for African Americans, 2016: trends in cancer incidence rates among Blacks, United States, 1975 to 2012. (From DeSantis et al. [6]. <http://onlinelibrary.wiley.com/doi/10.3322/caac.21340/full#caac21340-fig-0007>)



other Spanish decent [11, 12]. Data have shown that while Hispanics have 20% lower cancer incidence rates and 30% lower mortality rates compared to NHW, mortality rates are higher for adolescent Hispanic cancer patients [12]. Hispanics have lower incidence rates across the most prevalent cancers in the U.S. (i.e., prostate, breast, lung, colorectal; see Fig. 5.2). Despite lower general cancer incidence rates among Hispanics, trends suggest that Hispanics are more

likely to be diagnosed at later stages than NHWs. Further, Hispanic populations have higher incidence rates for specific cancers including acute lymphocytic leukemia, gallbladder cancer, and cancers associated with infectious diseases (e.g., stomach, liver, cervix, etc.) compared to rates among NHWs [12]. Liver cancer incidence and mortality rates remain consistently elevated among Hispanics compared to NHWs, with Hispanic men being twice as likely to have liver

Fig. 5.2 Cancer statistics for Hispanics/Latinos, 2015: trends in cancer incidence rates among Hispanics, United States, 1992 to 2012. (From Siegel et al. [12]. <http://onlinelibrary.wiley.com/doi/10.3322/caac.21314/full#caac21314-fig-0002>)



cancer than NHW men [11, 12]. Overall variations in cancer incidence between Hispanics and NHWs are hypothesized to be the result of both social contextual issues (e.g., nativity, environmental exposure to carcinogens) and behaviors that elevate cancer risk rates (e.g., obesity and diabetes) [13, 14].

Among Hispanic breast cancer survivors, many known factors have been shown to be associated with poorer outcomes (e.g., clinic visits, follow-up mammography) and less frequently adhered to among Hispanic survivors when compared to NHW survivors [9]. Results from a study designed to model health-related

quality of life among racial/ethnic minority breast cancer survivors with a large sample of Hispanic survivors suggest that sociocultural context (ethnicity, life stress, social support) explained 20% of the variance, demonstrating a larger influence than health status and behavioral factors (18%), demographic factors (14%), and health system factors (8%) [15]. Wu and colleagues suggest that an emphasis on the contextual impacts on health-related quality of life, specifically the impact of greater neighborhood stress on poorer health-related quality of life among ethnic minority (e.g., NHW) breast cancer survivors, is needed [10].

5.2.3 Asian-Americans, Native Hawaiians, and Pacific Islanders

The US Asian-American/Pacific Islander population is also a heterogeneous categorization describing a diverse subpopulation that includes Asian-Americans (e.g., Asian Indians, Cambodians, Chinese, Filipinos, Hmong, Japanese, Koreans, Pakistanis, Vietnamese, etc.), Native Hawaiians, and Pacific Islanders (e.g., Chamorros, Fijians, Samoans, etc.) (AANHPIs) [16]. Incidence data have consistently documented that while AANHPIs experience lower rates of cancer overall, the highest incidence rates within AANHPIs are attributed to breast, prostate, colorectal, and lung cancers (see Fig. 5.3). Additionally, AANHPIs have a disproportionately higher risk of developing cancers of infectious origins (e.g., hepatitis C, HPV) when compared to NHWs [16]. Cancer rates and risk vary widely among AANHPI subpopulations; therefore, cancer prevention, control, and survivorship strategies may benefit from considering these subpopulation differences [17, 18].

A mixed method study qualitatively described socioeconomic well-being (SWB) as a concern among US-born Chinese, immigrant Chinese, and NHW survivors [19]. The quantitative findings suggest Chinese immigrant survivors report the lowest SWB; however, across the study sample, women with lower incomes and recipients of chemotherapy reported low SWB. Generally, highly acculturated immigrant Chinese, US-born Chinese, and NHW survivors reported similar levels of SWB. More research is needed to develop knowledge about the complex cultural factors and contextual barriers specific to subpopulations of AANHPI in efforts to develop targeted and responsive interventions.

5.2.4 Native American/American Indian and Alaskan Natives

In the past two decades, American Indian and Alaskan native (AI/AN) populations benefitted less from progress to improve cancer mortality

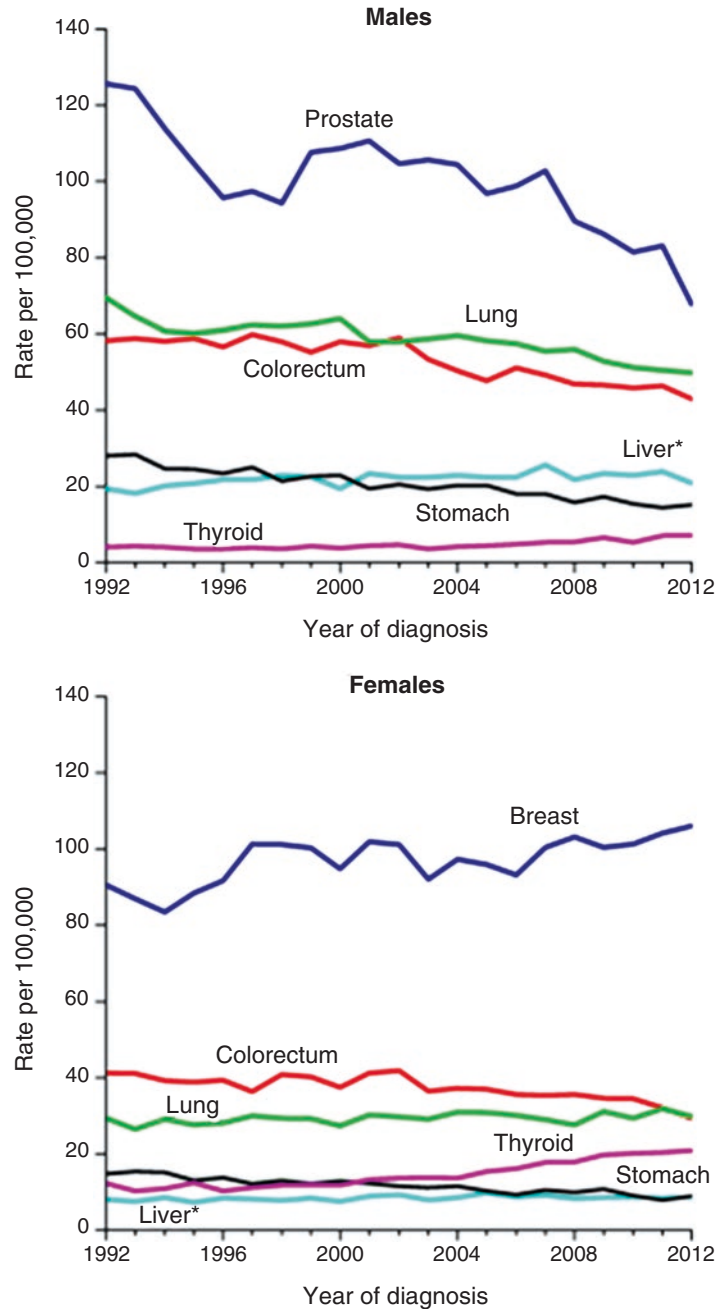
when compared to NHWs [20]. The presence of wider health disparities among AI/AN is demonstrated when geographical variations in mortality and incidence are considered [20]. These differences were in part attributed to contextual variation in lifestyle behaviors (e.g., cancer screening, tobacco use, obesity, etc.) [21]. Quality-of-life outcomes comparing AI/AN cancer survivors to non-AI/AN survivors found that AI/AN reported lower physical and social QOL, similar psychological QOL, and higher spiritual QOL [22].

Community-based participatory research projects such as the Native Navigators and the Cancer Continuum have shown promising results to engage community members and improve access to services among newly diagnosed and in building awareness about cancer-related resources [23]. Using a community-tailored approach, this investigation demonstrates the receptivity across AI/AN groups to build capacity toward improvements in cancer care. Explorations about how these efforts might influence different domains of cancer survivorship are needed [23].

5.2.5 Sexual Minorities

A 2011 Institute of Medicine report described the current lack of research regarding the health experiences of sexual minority populations, with gaps in the cancer literature spanning the cancer control continuum from prevention to survivorship [24]. Due to the lack of cancer surveillance data on sexual minorities, population-level data to assess incidence and risk factors specific to this population are lacking across the cancer continuum [25]. In a regional study conducted by Boehmer et al. [26], no significant difference in cancer prevalence among women by sexual orientation was reported. However, this study found lesbian and bisexual females had 1.0 and 2.3 greater odds of reporting poor or fair health compared to heterosexual female survivors. In contrast, men who have sex with men (MSM) had 1.9 greater odds of reporting a cancer diagnosis compared to heterosexual men [26]; however, no relationship between sexual orientation and self-reported health (e.g., ratings of health from

Fig. 5.3 Cancer statistics for Asian/Pacific Islanders 2015: trends in cancer incidence rates among Asian Americans, Native Hawaiians, and Pacific Islanders, United States, 1992 to 2012. (From Torre et al. [16]. <http://onlinelibrary.wiley.com/doi/10.3322/caac.21335/full#caac21335-fig-0006>)



excellent to poor) status was found among men. Studies have found no differences in quality of life between heterosexual, lesbian, and bisexual women [27, 28]; however, sexual minority women have been shown to have greater post-breast cancer treatment morbidity and systemic

side effects [29]. Survivorship research for less common cancer sites that impact women (e.g., cervical cancer) have been less well studied among sexual minority women [30]. Among MSM, higher prevalence for specific cancers has been attributed to sexually transmitted diseases

that are also more prevalent in the MSM population. Studies suggest that elevated rates of human papillomavirus (HPV) in MSM contribute to elevated risk for head and neck cancers [31] and anal cancers [32]. Further, documented human immunodeficiency virus (HIV) infection is associated with elevated rates of Kaposi's sarcoma, anal cancers, non-Hodgkin lymphoma, liver cancer, and lung cancer [29, 30, 33].

Population-based research that explores relationships between sexual minority status and cancer outcomes is limited overall; however, research within the transgendered population is particularly inadequate [34]. Among the transgendered population, conflicting evidence has been presented regarding the risk of breast cancer incidence [35, 36]. Case studies suggest the need to explore further cancer-specific risks related to the use of both masculinizing and feminizing hormones [24]. Additionally, evidence-based interventions are needed to inform nonjudgmental and knowledgeable approaches to long-term survivorship effects that specifically impact subpopulations of sexual minority survivors. For example, MSM posttreatment for anal cancers may endure long-term sequelae that present specific challenges to future intimacy, including sexual impairment and relationship adjustment to accommodate changes in functioning [30, 37]. Cultural competency training among health providers and the development of evidence to inform subpopulation-specific assessment and interventions have the potential to enhance quality of care [32, 40].

A major challenge to the provision of evidence-based care is that survivorship concerns specific to sexual minority subpopulations have not been well studied. Barriers to healthcare delivery for this population include a history of both institutional discrimination and interpersonal stigma (e.g., heterosexism, transphobia, etc.) directed toward sexual minorities from health professionals [38]. Sexual minorities in many cases must choose to disclose their gender identity or sexual behaviors to their providers. Many of the consequences during survivorship are related to identity, relationships, and sexuality; therefore, an initial step to develop culturally sensitive assessment and

intervention is fostering a safe environment for sexual minorities to disclose their gender identity and sexual behaviors to providers [39].

5.3 Implications of Disparities for Cancer Survivorship

Cancer survivorship is characterized by a long-term need to manage late- and long-term treatment effects. The impact of cancer treatment and its effect on cancer survivorship are differentially experienced by health disparity populations. This section explores the impacts of socioeconomic status, financial toxicity, and multi-morbidity on cancer survivorship health disparities.

5.3.1 Socioeconomic Status

The relationship between cancer and socioeconomic status (SES) is multifaceted and intersectional based on historical structural income inequalities among specific racial and ethnic subpopulations. Multiple factors including access to healthcare, screening utilization, behavioral risk, and occupational hazards strongly influence cancer incidence and are similarly associated with SES. Cancer incidence and mortality vary by SES in the United States [5, 6]. Low SES is associated with incidence and mortality rates for lung, colorectal, cervical [40], oral [41], and liver cancers [42].

Cancer incidence for other sites including breast, prostate, skin [40], and thyroid [38] are associated with higher SES [43]. In general, cancer incidence for sites that are associated with behavioral risk factors (i.e., tobacco use, alcohol, diet, intravenous drug use, and sexually transmitted infections) tends to be associated with lower SES [44]. Further research is needed to appreciate the impact of SES on QOL outcomes during cancer survivorship. Early insights regarding the breast cancer survivor population suggest that mental and physical health-related quality-of-life outcomes differed according to income, education, and job type, with survivors' belonging to higher

SES groups reporting better physical and mental health [45]. Additionally, these findings suggest that environmental stressors (i.e., housing situation, neighborhood, use of public services, violence exposure, and relations with the police) were the strongest predictor influencing physical and mental quality of life among breast cancer survivors [45].

5.3.2 Financial Toxicity

Across socioeconomic groups, financial toxicity (i.e., having high out-of-pocket costs that causes distress and impacts quality of life) post-acute treatment for cancer is now recognized as a major concern among survivors and has been found to be associated with higher mortality and distress [46]. This topic will be discussed briefly with a focus on disparity related to the cancer survivorship experience. A 2015 systematic review found that 16% to 78% of survivors experienced financial hardship as a result of their cancer [47].

A recent study found a consistent positive relationship between cancer survivors who declared bankruptcy and an increased risk of mortality (that varied in magnitude by cancer site) [48]. Racial and ethnic minority patients appear most vulnerable to financial decline attributable to breast cancer, even after adjustment for income, education, and employment [49]. Among insured individuals, a cancer diagnosis can prove financially catastrophic for patients and their families. Unfortunately, much of this research has focused on the impact of out-of-pocket costs among insured individuals and remains understudied among uninsured groups [50]. Financial toxicity as an adverse effect of cancer treatment can manifest as increased emotional and physical distress [46]. Financial toxicity has been found to be associated with poorer adherence to treatment [51] and poorer health-related quality of life among survivors in treatment and those with advanced cancer [52]. Given that financial concerns have been shown to contribute to survivors foregoing medical care, additional explorations into how cost is a driver for health-related disparities are needed [53, 54].

5.3.3 Multi-morbidity

Approximately 25% of Americans have multi-morbidity, defined as two or more concurrent chronic conditions that may include both physical (e.g., cardiovascular disease, diabetes, obesity, and cancer) and psychological conditions (e.g., depression and anxiety) [3], which may result in increased disability and impairment. Generally, cancer is an illness associated with aging, as well as high prevalence of multi-morbidity [55].

Evidence suggests that the number and severity of comorbidities at the time of a cancer diagnosis is strongly related to death due to non-cancer causes and cancer-specific mortality [56–59]. Health disparity populations are more likely to have multiple morbidities that require coordination of care for the management of several health conditions. Therefore, suboptimal survival outcomes among cancer survivors from health disparity populations are attributed, in part, to higher incidences of comorbidity that significantly contributes to increased disability and mortality [60–62].

Furthermore, health disparity populations often seek care in resource poor primary care settings [63]. In a study of racially diverse cancer survivors between the ages of 40 and 84 years, African-American women had the highest rates of chronic disease comorbidity (76%) followed by African-American men (70.6%) [64]. This finding and others suggest that the compound impact of cancer and comorbidity among African-Americans may be a significant contributor to poorer survival outcomes [61, 65, 66]. While survival is a key outcome, data are scarce on the impact of multi-morbidity on long-term health of cancer survivors and health disparate cancer survivorship populations. Additional research is needed to explore the impact of multi-morbidity on factors such as quality of life, self-management, and healthcare access and utilization.

5.4 Opportunities to Reduce Health Disparities

Cancer survivorship, similar to other transition points across the cancer care continuum, can be burdensome and difficult to navigate for low-income,

uninsured or underinsured, racial/ethnic minority, and other medically underserved cancer survivors who face additional barriers to accessing care and maintaining care continuity [67, 68]. The Institute of Medicine's 2013 report titled "Delivering High-Quality Cancer Care" declared a crisis in cancer care delivery [69]. This report and other studies document that low-income and racial/ethnic minority cancer patients, particularly those with Medicaid coverage or those without insurance, are more likely to experience delays in care, less likely to undergo cancer treatment, and have worse survival compared to privately insured or Medicare-insured groups. Many cancer patients who rely on charity/indigent care or emergency public insurance coverage during the diagnosis and treatment phases of the cancer care continuum face additional financial, geographic, and social barriers to receiving long-term follow-up care after active cancer treatment. Even among cancer patients with insurance, previously imposed lifetime insurance coverage limits and increasing out-of-pocket costs can cause severe hardships or affect access to necessary follow-up care [47, 54, 70].

5.5 The Affordable Care Act

The implementation of the Affordable Care Act (ACA) in 2010 resulted in 20 million Americans gaining health insurance [71]. Prior to the ACA, an estimated 14.7% of survivors were uninsured, and 18% of this population reported having a financial hardship. It was estimated that 30% of uninsured cancer survivors would become eligible for health insurance upon ACA implementation [72]. Approximately 2.1 million Medicaid enrollees are cancer patients or cancer survivors across the United States [73]. ACA coverage requirements specified the following provisions for patients with cancer, including coverage of cancer screening, preventive care, and clinical trials, as well as protections against lifetime spending caps, annual limits, and differential rates because of preexisting conditions [74]. These provisions are important for the prevention of

complex sequelae, as uninsured cancer survivors are less likely to receive preventive care, including cancer screenings [75], and are more likely to be diagnosed with later stage second cancers which have poorer prognosis [76]. While these important gains have provided proximal access to treatment and short-term follow-up as well as reduced financial hardship, it is unclear how proposed changes to the ACA will affect the receipt of cancer survivorship care across population subgroups in the years to come [77].

5.6 Care Transitions

In the US healthcare system, care transition points are replete with opportunities for system failures, and the transition from acute cancer care to post-acute care routinely lacks proactive coordination [78]. The Centers for Medicare and Medicaid Services (CMS) defines a transition of care as the movement of a patient from one setting of care to another. Settings of care may include hospitals, ambulatory primary care practices, ambulatory specialty care practices, long-term care facilities, home health, and rehabilitation facilities [79].

Following post-acute care, primary care providers are increasingly poised to be more involved in the follow-up care of survivors [80–85]. Yet, during the transition from acute cancer care to long-term cancer survivorship follow-up, patients are not confident with their PCP level of cancer follow-up expertise [86, 87], physician training and education on survivorship issues is limited [80, 88, 89], and barriers to patient and provider communications exist [86]. While several care transitions initiatives have been implemented or piloted by the Agency for Healthcare Research and Quality (AHRQ) or CMS to improve transitions between acute hospitalizations and long-term care or back to primary care [90, 91], few strategies have been developed to focus on improving the transition from active cancer treatment to long-term survivorship care.

5.7 Policy and Interventions to Reduce Health Disparities

Three broad strategies have been used to overcome the issues of fragmentation and coordination among the diverse cancer survivor populations: (1) the piloting of cancer survivorship models of care, (2) the development of survivorship care plans, and (3) the use of patient navigation services. The advent of cancer survivorship care models are often extension models already describing oncology settings [64, 92]. Most of these models implemented are extensions of oncologic care but vary widely in approach and scope of care based on the context where they are operationalized [64, 93]. This lack of standardization has been identified as a key care quality issue in survivorship care and remains a critical obstacle to developing strategies that are responsive to health disparity populations [2]. Further, studies of these survivorship models that have been piloted thus far have not consistently reported the proportion of non-White survivors who have access to these innovative new care models being studied [64, 94]. Unfortunately, no reliable information about how accessible cancer survivorship programs are to minority and underserved populations of cancer survivors in the United States is available [94].

The second strategy to overcome fragmentation during post-acute cancer care is separate, but related to piloted models of survivorship care, and is often a key focus of these models—the provision of a survivorship care plan (SCP). Survivorship care plans have been proposed as a communication tool intended to bridge the identified communication gap between patients, acute cancer care providers, and primary care physicians [95] and in some cases have been culturally tailored to address differences specific to subpopulations. A SCP can be a hard copy or electronic document that includes a personalized treatment summary, information on possible late- and long-term effects, signs of recurrence, guidelines for follow-up care cancer screening and surveillance tests, recommendations for healthy living, and identification of supportive

care resources [96–98]. The American College of Surgeons has made the provision of survivorship care plans a requirement for cancer center accreditation, which was endorsed by the American Society of Clinical Oncology as a step toward the delivery of higher-quality cancer care [99]. While primary care physicians are more likely to report engaging in survivorship care planning upon receipt of a care plan [100], evidence suggests care plans were not significantly efficacious in improving clinical and patient-reported outcomes [101, 102]. To date, no efficacy trials have investigated the feasibility of dissemination and potential impact of using survivorship care plans on clinical and patient-related outcomes in health disparity populations.

There are several potential reasons why SCPs may not fully address health disparities in cancer survivorship. Parry and colleagues [103] describe a “shortcoming of existing survivorship care planning is that it has not adequately addressed the diverse sociocultural backgrounds that survivors bring with them into the care context.” Because the emphasis is on transitioning survivors from acute cancer care to primary care, the current care planning process does not attend to whether survivors have a usual source of care. Recent studies have shown in non-Medicaid expansion states, cancer survivors were more likely to lack a usual source of care and report being unable to afford medical care [104].

Additionally, several studies have explored the acceptability of SCPs in minority populations and key findings indicate traditional SCPs: (1) are too technical, (2) use a “one-size-fits-all” communication strategy, (3) contain excessive medical jargon, (4) neglect psycho-social and self-care needs, and (5) do not provide sufficient information about late- and long-term effects of treatment [105–107, 86, 108]. These research studies have also noted that standard SCP templates do not sufficiently address well-documented factors such as personal beliefs and traditions; spirituality, culturally, and linguistically appropriate information; and medical mistrust that may impact their implementation [105, 109, 107, 110, 111, 108]. A 2013 study using

consensus meetings with survivors and advocates to identify culturally responsive SCP content and domains [105] found that SCPs lack patient input and adequate information on health histories, comorbidities, and health promotion. Recommendations to improve SCPs included documentation of all comorbidities and medications regardless of relationship to cancer, referrals for cancer-related providers, and culturally informed health advisories [105].

Studies that have sought to explore cultural adaptations of SCP content and delivery strategies provide many suggestions for culturally tailoring these tools based on the preferences and needs of specific populations. For example, Chinese-American breast cancer survivors preferred to receive their initial treatment summary face-to-face encounter with a provider, followed by a lay language written summary in English and Chinese [110]. A study of low-income survivor populations' concerns reported that a SCP should not replace direct communication with providers; however, there was a need to develop low-literacy written information in multiple languages [112]. Findings from research among African-American breast cancer survivors suggest that survivors received variable amounts of information about their cancer treatment and were unhappy with the cultural and race-specific information received [107].

The third strategy used to overcome health disparities are patient navigation services. Patient navigation services—a barrier-focused interventional approach to address and overcome fragmentation of care issues—have emerged as a strategy to address and overcome health delivery-related disparities across the cancer continuum for racial/ethnic minorities [113–116] and low-income [117, 118] and other urban underserved populations. These patient navigation strategies have utilized both medically trained staff and lay health workers and *promotoras*. According to a review of the state of the science regarding patient navigation, these efforts are largely focused on cancer screening, diagnosis, treatment, and clinical trial enrollment [119]. Although a qualitative study of African-American breast cancer survi-

vors describes the need for continued navigation during post-acute care [120], to date, no efficacy studies have evaluated the impact of patient navigation services on survivorship outcomes [119]. Currently, there is no other research to inform this area regarding disparity groups; therefore, subsequent research to expand the evidence base and articulate best practices for patient navigation during the cancer survivorship phases of care are warranted.

5.8 Future Directions

Evidence regarding the incidence and mortality for key racial and ethnic minority subpopulations in the United States is readily available and can assist in the development of cancer prevention and control strategies to address health-related outcomes. However, additional research is needed to further elucidate drivers of health disparity cancer survivorship outcomes at the individual, social, and health system process levels that contribute to physical and mental health quality of life during survivorship, from the period of post-acute cancer care to the end of life. The current race and ethnicity data collected nationally in datasets such as NCI's Surveillance Epidemiology, and End Results (SEER) are systematic but not comprehensive; therefore, the current practice of lumping smaller subpopulations together into heterogeneous groups to achieve larger samples makes it difficult to discern whether trends noted at the population level translate into actionable data for use at the individual, social, and health system process levels. While race and ethnicity data are insufficient, there is a lack of data regarding sexual minorities health research as documented in the recent IOM report [24], and current national resources such as the SEER database do not collect data on sexual orientation or gender identity. Therefore, to address health disparities in cancer survivorship, we need more data about individual groups for tailoring and use in design and implementation of specific cancer prevention and control program and policy-making efforts.

There is also need for interventions to address the disproportionate burden of multi-morbidity in particular among the underserved. The need to further tease apart the cumulative impact and relationships between obesity, comorbidities, race, and ethnicity on cancer survival and survivorship outcomes has been articulated elsewhere [14]. Additionally, the potential impact of financial toxicity on poorer health outcomes among health disparity populations is an area in need of additional attention. Much of the focus thus far has been on the impact on insured populations [50], whereas more studies of the uninsured and underinsured are needed. Further, existing SCPs do not adequately address the needs of diverse minority populations [105, 107, 110, 109]. The potential of survivorship care plans that incorporate the culture, values, and beliefs of minority cancer survivors to reduce barriers in communication and improve coordination of care is an area in needs further research [107, 105, 121, 122].

The issues described above point to a growing appreciation for the development of multi-level interventions [123]. Interventions that move beyond framing health outcomes as the result of individual choice and instead acknowledge that health is the result of individuals and groups navigating complex social and political environments are needed [124]. Inequalities based on race, income, and sexual identity should be conceptualized from an intersectional approach that understands that vulnerabilities for health disparities may be multiplied and compounded [125]. As is the case for many health issues, disparities in cancer survivorship manifest at multiple levels, such as home/family, community, region, state, and health service delivery. Therefore, issues such as poverty, race, and how these manifest within communities influence crucial behaviors. Policy can shape health system responses that impact the cancer survivorship phase of care. It is important that cancer survivorship disparity research evolve to address this multilevel, social ecological context.

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