

OPTIMIZATION OF FUNCTION AND HEALTH-RELATED QUALITY OF LIFE IN  
ADULT CANCER SURVIVORS

by

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## ABSTRACT

Optimization of Function and Health-Related Quality of Life in Adult Cancer Survivors

Amanda Gehrke, MS

Thesis directed by: Michael Feuerstein, PhD, MPH, Professor (Retired), Departments of Medical and Clinical Psychology and Preventive Medicine and Biostatistics

*Background.* A large subset of cancer survivors experience acute, long-term, and/or late effects, as well as comorbid health conditions, which can negatively impact their function and health-related quality of life (HRQOL). This series of studies evaluated approaches developed to optimize function and HRQOL in adult cancer survivors in the healthcare setting and the workplace. *Studies.* Studies 1 and 2 focused on the application of the Americans with Disabilities Act (ADA) Amendments Act (U.S. workplace discrimination law) in cancer survivors; both studies utilized logistic regressions to examine ADA claims information. Study 1 evaluated the association between the Amendments Act passage and claims filed by cancer survivors. Findings indicated that discrimination allegations were more likely to be filed in the areas of workplace relations (OR = 1.48, 95% CI = 1.23-1.78) and terms of employment (OR = 1.34; 95% CI = 1.11-1.61) under the Amendments Act. Study 2 examined protections for cancer survivors with comorbid health conditions under the Amendments Act. Findings indicated that cancer survivors with comorbidities were more likely to file claims related to the terms of their employment (OR = 1.37, 95% CI = 1.04–1.80) than cancer survivors without comorbidities. Study 3 focused on developing a communication and self-management tool (CSPro app) to help address unmet needs post-active treatment for breast cancer.

This study included app development, collection of breast cancer survivor and nurse perceptions of the app within a clinical oncology setting, and changes made to the app based on this feedback. Findings indicated that the CSPro app was efficient, comprehensive, and well-received by both nurse navigators and cancer survivors.

*Implications.* This programmatic series of studies indicates that current approaches to optimization of function and HRQOL in the healthcare and work contexts are helpful but not sufficient. It also suggests adjuncts to these approaches, such as utilization of medical providers (in the case of work function), and addition of tools such as the CSPro app (in the case of healthcare) are needed. Critical next steps include continued development of policy-level approaches, and an openness to and acceptance of new clinical efforts designed to improve function and HRQOL.



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## **CHAPTER 1: Program of Research**

### **EPIDEMIOLOGY**

There are approximately 15.4 million adult cancer survivors (i.e., individuals with a history of cancer) living in the U.S. today (104). Slightly more than half of these cancer survivors (8.1 million) are women. The most prevalent cancers in women include breast, uterine corpus, and colon and rectum, while the most common cancers in men are prostate, colon and rectum, and melanoma. Approximately 89% of cancer survivors are age 50 or older, with prevalence generally increasing with age and peaking around age 70-79 (50-59: 15%, 60-69: 27%, 70-79: 26%, 80+: 21%) (104).

As screening and treatment approaches improve, cancer survivors are living longer (104). Currently, approximately 23% (3,530,890) of cancer survivors are between 5 and < 10 years out from diagnosis, 16% (2,493,340) are between 10 and < 15 years post-diagnosis, and 6% (921,550) are 30 or more years post-diagnosis. As treatment advances continue and the population ages, the duration of survival is expected to increase and the cancer survivor population is expected to grow, with an estimated 26.1 million U.S. cancer survivors projected by 2040 (11) .

### **FUNCTION AND HEALTH-RELATED QUALITY OF LIFE**

Cancer is increasingly being conceptualized as a chronic illness (96; 127; 136). Approximately one third to one half of cancer survivors experience acute, long-term, and late effects that can negatively impact their health-related quality of life (HRQOL) and function (139; 152). HRQOL challenges are reported in the areas of body image (82), fatigue (3; 68; 148), fear of recurrence (75; 120; 122), pain (15; 46), and psychological

distress (60; 147). Functional challenges are described in a range of domains including: financial (153), social (43; 78; 83; 150), cognitive (4; 67), sleep (37; 79), sexual (27; 70; 113), diet (8; 115; 116), physical activity (12; 33), work ability and sustainability (22; 32; 128; 142), accessing and understanding health information (42; 51; 119), effectively communicating with healthcare provider (19; 41; 111), and feeling competent in managing one's own health (44; 54; 74). Additionally, a recent evaluation of a nationally representative sample indicated that, when compared to their non-cancer counterparts, cancer survivors were more likely to report pain (OR = 2.1; 95% CI=1.7 to 2.6), fatigue (OR = 1.4; 95% CI = 1.1 to 1.8), sensation abnormality (OR = 2.4; 95% CI = 1.9 to 3.0), and a reduced physical HRQOL (difference=-3.7; 95% CI=-4.7 to -2.6) (63).

Cancer survivors also often have one or more comorbid conditions, including psychological difficulties (e.g., anxiety, depression), as well as other medical conditions (e.g., diabetes, heart disease, arthritis). In U.S. working age cancer survivors (18-64), about 74% of recent ( $\leq 1$  year post-diagnosis) and 73% of longer-term ( $> 1$  year post-diagnosis) survivors have one or more comorbid chronic medical condition, as compared to 47% of working age adults without a history of cancer (50). In older U.S. cancer survivors (66+), approximately 1/3 to 1/2 have one or more comorbid conditions, depending on their cancer type (31% prostate, 32% breast, 41% colorectal, and 53% lung), as compared to 1/3 of non-cancer adults (36). In this older cancer survivor population, the most prevalent comorbid conditions generally include diabetes (16%), COPD (16%), congestive heart failure (10%), and cerebrovascular disease (6%) (36). Longer-term cancer survivors (4-14 years post-diagnosis) across a wide age range (21-79 years old) report having five other, non-cancer medical conditions (i.e., conditions

involving the heart, circulation, central nervous system, eye/ear, neuropathy, lungs, liver, gastrointestinal, kidney, thyroid, bone, hypertension, diabetes, depression, anxiety, anemia, arthritis) on average (81).

The presence of comorbid conditions, as well as acute, long-term, and late effects, is often negatively associated with mental and physical function and overall HRQOL. A recent evaluation of a nationally representative sample indicated that, in cancer survivors, pain (beta=-4.0; 95% CI=-4.5 to -3.6) and the presence of  $\geq 2$  chronic conditions (beta=-9.2; 95% CI=-10.2 to -8.2) were related to reduced physical HRQOL, while depression (beta=-5.2; 95% CI=-5.8 to -4.6) and the presence of  $\geq 2$  chronic conditions (beta=-3.3; 95% CI=-4.4 to -2.3) were related to reduced mental HRQOL (63). A range of interventions exist to target acute, long-term, late effects, and symptoms related to comorbid health conditions (12; 16; 18; 66; 96; 101; 115; 126). However, these symptoms, functional difficulties, and comorbidities remain a challenge in this population (17; 18; 93).

## **CURRENT APPROACHES AND GAPS**

Two contexts in which these needs usually present in adult cancer survivors include the workplace and the healthcare setting. Research in these areas has increased a great deal over the past decade and corresponding clinical and policy changes have followed. However, there is still much work to be done (93; 139).

### **Healthcare Setting**

Currently, a primary focus of healthcare research, policy, and clinical work is on care during the transition from active treatment (i.e., chemotherapy, radiation, and/or surgery) to the post-treatment phase, and beyond (103). Cancer survivors have

historically been "lost in transition" during this phase (65) and many cancer survivors continue to report unmet needs in this care (17; 45). Appropriate survivorship care following active treatment is critical in helping cancer survivors effectively manage challenges related to acute, long-term, and late effects.

While a range of models have been proposed for post-treatment survivorship care (103), the most widely adopted has been the treatment summary and survivorship care plan (14; 72; 91; 102). Treatment summaries provide a written or electronic document detailing all cancer-related treatments received. Survivorship care plans typically include a series of questions covering potential long-term and late (primarily medical) effects. There are a variety of survivorship care plans publicly available (see <https://www.cancer.org/treatment/survivorship-during-and-after-treatment/survivorship-care-plans.html> for a selection). Healthcare providers (generally nurse navigators (48)) are encouraged to review these documents with patients during their transition from active treatment to the conclusion of active treatment and/or no evidence of a malignant growth. Survivorship care plans have a great deal of face validity and have been widely accepted in clinical care. Additionally, they are even required by the Commission on Cancer of the American College of Surgeons (by 2019). However, the evidence on the clinical benefit of survivorship care plans is still mixed (14; 25; 72; 91) and cancer survivors continue to report unmet needs in survivorship care (69; 93; 94).

As a result of inconclusive evidence and continued unmet needs, development of adjuncts to survivorship care plans have begun to emerge (80; 135; 140; 141; 151). These approaches tend to focus on self-management (61; 141). Self-management interventions for individuals with chronic conditions target the following core skills: problem solving,

decision-making, finding and utilizing resources, forming partnerships with health care providers, taking action (i.e., generating an action plan and following through on it), and self-tailoring (i.e., applying knowledge and skills to oneself, as appropriate) (86). Two primary outcomes of these types of self-management interventions include patient activation (i.e., the ability to be an engaged and active member in one's own care) (57; 124) and chronic disease self-efficacy (i.e., perceived competence in managing one's own health) (87; 110).

Both self-efficacy and patient activation have been shown to predict intent and actual follow-through in managing health challenges (44). In individuals with a history of cancer, chronic disease self-efficacy has been positively associated with generic HRQOL ( $r=-0.65$ ,  $p<0.001$ ; higher score indicates lower HRQOL), cancer-specific HRQOL ( $r=-0.52$ ,  $p<0.001$ ; higher score indicates lower HRQOL), well-being ( $r=0.75$ ,  $p<0.001$ ), and social support ( $r=0.53$ ,  $p<0.001$ ), and negatively associated with depressive symptoms ( $r=-0.75$ ,  $p<0.001$ ) (44). In a review of breast cancer survivors specifically, self-efficacy has been shown to be positively associated with quality of life and emotional wellness, and negatively associated with fatigue and distress (105). Based on a recent review (55), patient activation is positively associated with preventive behaviors, disease-specific self-management behaviors, adaptive health behaviors, certain biomarkers, and healthcare seeking skills (e.g., preparing questions for medical visit, awareness of relevant treatment guidelines), and rates of hospitalizations and emergency department visits, and negatively associated with substance use, unmet medical needs, and seeking timely medical care. Additionally, patient activation is positively related to the physical and mental health components of the a health-related quality of life measure,



the SF-36 (123). In cancer survivors, specifically, patients with higher levels of activation are more likely to effectively cope with treatment side effects (OR = 4.49,  $p = 0.00$ ), initiate a healthier diet after diagnosis (OR = 3.3,  $p = 0.00$ ), exercise more (OR = 4.7,  $p = 0.00$ ), and be satisfied with their care ( $F(2, 440) = 18.7, p < 0.000$ ) (56). Those with less activation demonstrate a lower likelihood of following through on their provider's recommendations ( $F(2, 498) = 6.4, p < 0.000$ ).

Given these factors, self-management adjuncts targeting activation and self-efficacy hold great promise for reducing unmet needs in cancer survivors. One such adjunct, which was recently developed, is called the Cancer Survivor Profile (CSPro) (135). The CSPro is a communication tool for cancer survivors and nurse navigators to utilize following completion of active cancer treatment. It aims to efficiently evaluate and provide feedback about a range of areas related to health, psychosocial well-being, function, and health behavior. It was developed to directly address current gaps in follow-up care for cancer survivors and is designed to promote self-management through self-assessment and identification of problem areas, facilitation of patient-provider communication, and provision of problem-specific resources (135). While the CSPro demonstrates acceptable psychometric characteristics, it has not yet been evaluated as an intervention.

## **Work**

While interventions in the healthcare setting directly target cancer survivors' HRQOL and function, treatment and experience in the workplace also greatly impact these outcomes. Many individuals with cancer and other chronic conditions report a desire to return to or remain at work, explaining that it provides them with feelings of

normalcy, a source of identity, financial support, and socialization (118). However, a large subset of cancer survivors report difficulty returning to or remaining at work (22; 32; 99; 142) and describe experiencing discrimination and stigma related to the workplace (39; 128). Workplace discrimination can negatively affect both quality of life (e.g., physical and mental health), as well as work function (e.g., work ability, productivity) in cancer survivors (40; 106)

Cancer survivors with comorbid conditions are particularly vulnerable to workplace challenges. Compared to U.S. working age adults without a history of cancer, U.S. working age cancer survivors have a disproportionately high prevalence of one or more comorbid conditions (50), report poorer overall health (22), and take significantly more missed work days due to illness/injury (149). In these survivors, the presence of one or more chronic conditions is associated with a reduced probability of employment (30) and, for those who are employed, a reduced perceived work ability (32).

Advocates for individuals with chronic health conditions, including cancer, have emphasized the important role of legal policy to address and/or prevent a number of workplace problems. In the U.S., these efforts led to the Americans with Disabilities Act (ADA). The ADA was passed in 1990 and was intended to protect individuals with serious health conditions from workplace discrimination. This law applies to employers with fifteen or more employees and was designed to protect affected workers from discrimination in the areas of: hiring (e.g., prohibited medical inquiry), terms of employment (e.g., passed over for promotion), reasonable accommodations (e.g., lack of accommodations), relations (e.g., poor treatment), and termination (e.g., involuntary retirement). If an employer violates conditions of the employment protection law, an

employee can pursue legal action by filing an ADA claim or allegation. The terms allegations and claims are synonymous; these words are used interchangeably in this proposal.

Evaluation of allegation data under the ADA has previously indicated that cancer survivors were more likely to file claims related to termination and terms of employment, as compared to other chronic illness groups (39). Additionally, cancer survivors with comorbid conditions were more likely to file allegations in the both terms of employment (OR = 1.47, 95% CI = 1.16-1.87) and relations (OR = 1.58, 95% CI = 1.22-2.04), as compared to cancer survivors without comorbid conditions (39). Furthermore, when compared to other disability categories covered by the ADA, allegations filed by cancer survivors were more likely to be favorably adjudicated ( $Z = 9.63, p < 0.001$ ), indicating credible allegations from the perspective of the employee; the impact of comorbid health conditions on legal outcome in cancer survivors was not examined (97).

While the ADA was intended to address discrimination problems related to serious health conditions, such as cancer, epilepsy, diabetes, major depression, and bipolar disorder, it has been criticized as having limited applicability to employees with these health problems due to its narrow definition of “disability”, as interpreted by a series of Supreme Court Rulings (134). As a result, on September 2008 the ADA Amendments Act was created (133). It became effective on January 1, 2009 and on March 25, 2011 the final regulations were published by the Equal Employment Opportunity Commission (EEOC).

While a full review of the ADA and ADA Amendments Act is beyond the scope of this proposal (see Benfer (9) and Hickox (58) for more detailed information), it is

important to note that the ADA Amendments Act and associated EEOC guidelines maintained the ADA definition of disability: “(A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual, (B) a record of such impairment, or (C) being regarded as having such an impairment”, but elaborated/clarified the terms “impairment”, “substantially limits”, and “major life activities” to allow for more employees to fit within the definition of a qualified condition (133). Legal opinion related to the impact of the ADA Amendments Act on cancer survivors has concluded that has made it “easier” for cancer survivors (in general) to fall into the category of “protected” by the law (59).

The revised ADA Amendments Act was intended to provide increased access to the antidiscrimination laws for many with chronic illness. Evaluating discrimination allegations in the context of the revised law would provide updated information on the specific challenges cancer survivors face under the revised Amendments Act, including both type of discrimination and its verification by third party evaluation (i.e., EEOC or federal courts).

## **CURRENT SERIES OF STUDIES**

Three studies were conducted to address the above limitations. This included two studies in the area of policy, both evaluating a policy intended to prevent or reduce levels of work-related discrimination in cancer survivors (studies 1 and 2), as well as one in the area of health care improvement, specifically for breast cancer survivors (study 3). All of these studies evaluated approaches intended to optimize function (work and health self-management) and HRQOL in adult cancer survivors.

## **Work**

The two studies in the area of work (studies 1 and 2) focused on evaluating workplace discrimination protections for cancer survivors under the ADA Amendments Act. The purpose of study 1 was to determine whether the ADA Amendments Act was related to changes in workplace discrimination allegations in cancer survivors in general. The purpose of study 2 was to evaluate the current state of workplace discrimination and ADA protection in a more vulnerable group, cancer survivors with comorbid health conditions, compared to cancer survivors without comorbid conditions. The ADA Amendments Act was intended to increase coverage of individuals with chronic health conditions against discrimination, allowing for optimization of function and quality of life within the workplace. Data on how cancer survivors both with and without comorbid health conditions are faring under this new Amendment would help to inform cancer survivors, non-cancer employees, employers, health care providers, and policy makers in the U.S. about residual challenges faced by this group. This information could also be useful for developing appropriate support at the individual, organizational, national, and international levels.

## **Healthcare**

Study 3 focused on healthcare improvement for breast cancer survivors. The purpose of study 3 was to develop an app version of the CSPro, deliver it in a clinical oncology setting, and obtain feedback on its components from breast cancer survivors and nurse navigators. The CSPro app consisted of the CSPro survey (evaluating 18 different potential problem areas), a graphic profile of problem areas, and provision of problem-specific online resources. Development included working with an app

development company to create an app that administers the CSPro, correctly scores it (including calculating t-scores using data from a reference group and adjusting for social desirability where indicated), then automatically generates a graphic profile highlighting areas of concern (above a certain t-score) and a corresponding set of problem-specific online resources across a range of formats (e.g., website, podcast, app, social media). Testing focused on evaluating patient and nurse navigator perceptions of the app, including ease of use, clarity of display, comprehensiveness of problem area coverage, and utility as a communication tool in the clinical oncology setting. The app was then optimized based on this feedback.

## **Conclusion**

This programmatic series of studies addressed certain current gaps in the research literature on cancer survivors and contributed to efforts aimed at improving functional outcomes related the work and health self-management, as well as HRQOL.

## **CHAPTER 2: Study 1—Challenges Persist Under Americans With Disabilities Act Amendments Act: How Can Oncology Providers Help?**

### **INTRODUCTION**

In the United States, approximately 9.9 million working-age adults (18 to 64 years) have a history of cancer (10). Many of these individuals need, and/or choose, to retain some level of employment after primary treatment of cancer. Work provides not only a certain level of income but also a sense of normalcy and social support (73; 114). A subset of patients with cancer and survivors (post primary treatment), however, report physical (eg, pain, fatigue, cognitive limitations) and psychosocial (eg, anxiety, depression) long-term and late effects after their cancer diagnosis and/or treatment, which can negatively affect their ability to return to or remain at work (29; 99). Those with a history of cancer can experience stigma and discrimination in the workplace as well (90; 100; 139).

In 1990, the Americans with Disabilities Act (ADA) was passed to protect individuals with various impairments (ie, behavioral, sensory, neurologic, or medical conditions, including cancer) that substantially limit a major life activity, such as work, from discrimination. The law was intended to protect individuals in workplaces with  $\geq 15$  employees. Specifically, the ADA was designed to provide legal coverage against discriminatory action in the areas of: hiring practices (eg, prohibited medical inquiry), terms of employment (eg, denying promotion), relations (eg, harassment), provision of reasonable accommodations (eg, failing to offer a flexible work schedule to facilitate medical appointments), and termination of employment (eg, involuntary retirement). If a

personnel action was related to the existence or consequence of a disability, an employee could file an allegation of discrimination under Title I of the ADA.

Analysis of allegations filed under the original ADA indicated that those with a history of cancer were more likely than other impairment groups (eg, orthopedic, cardiovascular) to file allegations related to termination and workplace policies (39). It has also been documented that certain allegations filed by individuals with a history of cancer (eg, failure to provide reasonable accommodations) were determined in favor of these individuals, in contrast to allegations filed by those with non-cancer-related impairments (97). Although the original ADA provided protection to those with a history of cancer, when these employees no longer had clear evidence of a tumor, or were determined to be in remission, they became ineligible for ADA coverage. That meant that when a cancer survivor experienced difficulty with a long-term and/or late effect of their cancer or cancer-related treatment that influenced their work ability (eg, fatigue), they were no longer protected by the ADA (134).

In 2008, the ADA Amendments Act was passed, and on January 1, 2009 it became operational. The Amendments Act provided a more inclusive definition of impairment, which more accurately reflects the natural history of many chronic illnesses. The Amendments Act indicated that the employee maintains their status as an American with a disability even when the impairment is in remission, or symptoms are managed through medications, making coverage more inclusive. In this way, the ADA Amendments Act improved coverage for individuals with cancer undergoing active treatment and expanded coverage to individuals who may have been denied in the past. Since the passage of the Amendments Act, inclusion under the ADA continues to require



that the impairment substantially limit a major life activity when the health problem is active. Allegation types continue to include those related to hiring practices, employment (ie, discrimination in terms of employment, adverse relations in the workplace, and failure to provide reasonable accommodations), and termination. Table 1 lists workplace discrimination actions included in each allegation type. A detailed review of the ADA and its Amendments is beyond the scope of this article. For a full review of this topic, please refer to Benfer (9) or Hickox (58).

With its more inclusive definition of disability, the ADA Amendments Act potentially provides a broader safety net for those with different types of illnesses and has made it easier for those with a history of cancer to fall within the category of a protected group (59). However, it is not known whether this increase in coverage is related to changes in any type of allegation of workplace discrimination. It is also unclear whether the legal merits of these allegations (ie, independent support for the existence of discrimination) changed when the more inclusive act was implemented. Because the ADA is presumed by many to protect those with a history of cancer, it is important to determine whether the implementation of the Amendments Act is actually associated with changes in specific allegation types and merit of these allegations, as determined by review from independent regulating bodies (ie, the Equal Employment Opportunities Commission [EEOC] or federal courts). Merit was used in this study as a proxy for the presence of workplace injustice. This information can better inform oncologists and other providers when working with patients who desire or need to work.

## **METHODS**

### **Data Source and Sample**

A subset of the EEOC's Integrated Mission System data, maintained by the National EEOC ADA Research Project, was used for all analyses. Records were supplied in a Microsoft Access file and were converted to IBM SPSS Statistics Version 22 for analysis. Data from the post-Amendments Act period included allegations filed from 2009 to 2011 by individuals with a history of cancer. The pre-Amendments Act comparison group included allegations filed from 2001 to 2008 by individuals with a history of cancer.

The variables of sex; age; race; employer industry, region, and size; number of allegations filed; specific allegation types (ie, hiring, terms of employment, relations, reasonable accommodations, and termination); and merit of the allegations, as determined by the EEOC or federal courts, were provided. To maintain consistency with the typical working age range in the United States, the present analyses were restricted to claimants ages 18 to 64 years. Individuals for whom age was not reported were excluded from the data set. Variables with sufficient data (ie,  $\leq 10\%$  missing per group) were retained. Race and employer industry had  $> 10\%$  of data missing for both groups of claimants and, therefore, were not included in the analyses. Analyses only included claimants with full sets of data on all retained variables; 11% of claimants ( $n = 308$ ) were excluded from the analyses because of incomplete data for these retained variables. There were no significant differences on demographic (age, sex), employer (region, size), or allegation (type, merit) characteristics between the retained and deleted cases.

### **Data Analysis**

The independent variable for all primary analyses was allegation time frame (post v pre Amendments Act; dichotomous). Primary dependent variables included: outcome

of EEOC or federal court investigation (dichotomous; allegation has merit or no merit) and allegation type (categorical). Because more than one allegation can be filed per individual, each allegation type—hiring, terms of employment, relations, reasonable accommodations, and termination—was analyzed separately as a dichotomous variable (ie, filed or not filed). For all main analyses, potential confounding variables were identified statistically using the Hosmer and Lemeshow technique; variables at  $P < .10$  were retained (62).

Five separate stepwise multivariable logistic regression analyses were conducted to determine the association of time frame of allegation (post v pre Amendments Act) with type of allegation. Separate regressions (step 1: potential confounders, forward conditional; step 2: time frame of allegation, forced entry) were used for each allegation type. Potential confounding variables evaluated for inclusion were sex (dichotomous), age (continuous), employer size (categorical), and employer region (categorical). The logistic regression evaluating hiring-related allegations was adjusted for employer size and sex, and the remaining four regressions were adjusted for employer size, employer region, and sex.

A stepwise multivariable logistic regression (step 1: potential confounders, forward conditional; step 2: allegation types—hiring, terms of employment, relations, reasonable accommodations, and termination, forced entry) was also conducted to identify the relationship between time frame (post v pre Amendments Act) and merit of allegation for each allegation type. Potential confounding variables evaluated for inclusion in the models were sex (dichotomous), age (continuous), employer size (categorical), employer region (categorical), and number of allegations filed (categorical).

Confounding variables included in the analysis were employer size, employer region, and number of allegations filed. They were entered into the model as interaction terms (ie, confounder X time frame of allegation [post v pre Amendments Act]).

## **RESULTS**

### **Characteristics**

The final sample included 1,209 pre-Amendments Act and 1,291 post-Amendments Act claimants. Claimants ranged from age 20 to 64 years at the time of filing, were on average 49 years old, were primarily female (65%), and worked at small (ie, 15 to 100 employees; 31%) and large companies (ie,  $\geq$  501 employees; 44%) distributed across geographic regions, with the largest subsets from the Midwest (23%) and Southeast (26%). Age, sex, and employer size remained stable between pre- versus post-Amendments Act phases, whereas employer region and number of allegations fluctuated somewhat. There was a significant increase in claimants from the Southwest (13% to 18%;  $P < .05$ ); all other regions remained stable. The number of claimants filing only one allegation decreased over time (43% to 36%;  $P \leq .001$ ), whereas those filing two allegations remained relatively stable (approximately 30%), and those filing three or more allegations increased over time (23% to 32%;  $P \leq .001$ ).

### **Allegations and Merit Post Amendments Act**

Distributions of allegation type pre and post Amendments Act can be seen in Table 1. Stepwise logistic regressions indicated that claimants were more likely to file allegations related to terms of employment and relations at work during the post-Amendments Act period (odds ratio [OR], 1.34; 95% CI, 1.11 to 1.61; and OR, 1.48;

95% CI, 1.23 to 1.78, respectively). All other allegation categories (ie, hiring, reasonable accommodation, and termination) remained stable.

A little over a quarter (28% to 29%) of claimants in the pre- and post-Amendments Act phases filed allegations that were determined to have merit. The stepwise logistic regression for merit indicated that allegations involving terms of employment were more likely to be deemed meritorious during the post-Amendments Act period (OR, 1.35; 95% CI, 1.03 to 1.77). All other allegation categories (ie, hiring, relations, reasonable accommodation, and termination) remained stable. Results of both analyses can be seen in Table 2. Table 3 lists two case examples to further clarify the types of challenges observed in practice as well as select resources that may assist in self-learning.

## **DISCUSSION**

Workplace discrimination continues to challenge those with a history of cancer. Results indicate that patients with cancer and cancer survivors were more likely to file allegations involving terms of employment (eg, withholding promotion, forcing retirement, denying wage increases, ignoring seniority) and strained relations (eg, harassment, intimidation, breach of confidentiality), even after the implementation of the more inclusive ADA Amendments Act. The allegations involving terms of employment were also more likely to be judged as having merit, supporting the validity of these allegations. Beyond these two areas, allegations filed and their concomitant merit remained stable, despite the implementation of the more inclusive Amendments to the ADA. In no area were claimants less likely to file allegations post Amendments Act.

The present findings are consistent with what is currently known about cancer and work. Modifications in work productivity have been observed after initial diagnosis and treatment (154). This reduced productivity can increase frustration in both employer and employee. Direct avoidance of cancer survivors (ie, breast, prostate, testicular) by others in the workplace (ie, supervisors or colleagues) and lower levels of perceived work ability have also been reported (85). Cancer-related stigma in the workplace can be present and is influenced by long-held misconceptions and fears that cancer is a death sentence (128). In addition, workers with a history of cancer are considered by some as unreliable and significant cost drivers, often due to workplace accommodations and lost time (128). As is well known, some cancer survivors experience persistent or episodic exacerbations in long-term effects, whereas others can experience marked improvements in symptoms and function over time (52). As the prevalence of cancer survivors increases (11), and the trend of delaying retirement becomes more commonplace, the stigma of cancer in the workplace and cancer-related discrimination may become more common.

The importance placed on the role of communication between employers and employees with chronic illness has been emphasized for years, and, as simple as it sounds, it cannot be underestimated. Despite the more inclusionary change in workplace protections with the ADA Amendments Act, allegations have persisted (ie, hiring, reasonable accommodations, termination) and actually increased in two areas of workplace discrimination (ie, terms of employment and relations). Workplace discrimination overall may be preventable with increased communication, greater flexibility on the part of stakeholders, and sincere attempts at reasonable accommodations. Indirect support for the importance of communication facilitated

accommodation is provided in a recent survey of cancer navigators (143). These navigators reported that proactive workplace accommodations may help to partially mitigate, or prevent, negative workplace outcomes in areas related to conflicts between workplace demands and treatment schedules and even job termination. It is exactly these accommodations that can evolve from effective communication among employer, employee, and health care provider. A positive relationship between accommodation at work and improved work outcomes, such as employment sustainability and increased hours worked, has been observed (40). Although causation cannot be determined and productivity changes were variable, depending on the type of accommodation (109), many employers are open to suggestions for workplace accommodations in cancer survivors (109; 129). Together, these findings suggest that involvement by the oncology health care team can play an important role and would be a welcomed addition.

The challenge of getting employers and employees with a history of cancer to work together in this area may be explained, in part, by a lack of flexibility. Employees might expect that, because of their illness, they should be given flexibility regardless of reduced productivity. On the other hand, supervisors may expect that the affected employee should just return to pretreatment levels of productivity, without any workplace modifications, particularly after treatment of a curative nature (109). This discrepancy in expectations, when persistent, may exacerbate a sense of perceived injustice, especially when the employee experiences such actions as lost or reduced wages and relationship problems with supervisors or others in the workplace. Direct and early communication between employer and employee can address differences in expectancies. It is likely that perceived injustice is experienced by both parties and can contribute to limited

communication and strained relations (eg, perceived harassment, reduced productivity). This speculation requires empirical verification.

The present results are limited to applicants and current or past employees who actually filed allegations of discrimination. Given the potential stigma and job stress that can be associated with allegations of workplace discrimination, it is likely that there are some employees for whom discrimination goes unreported. In addition, there are many employees with a history of cancer who do not experience problems in the context of work. It is also important to note that it is possible the differences in the allegations and merit observed pre versus post Amendments Act are simply the result of secular changes and not due to specific changes in the ADA. Secular changes can be an inherent source of bias in natural experiments. Despite these caveats, the current findings indicate that patients with cancer and survivors report discrimination, validated via meritorious rulings of certain disputes by the EEOC or federal courts.

It is not reasonable for oncology providers to address all the challenges that a patient with a history of cancer can experience in the workplace (eg, discrimination related to hiring). However, oncologists and the oncology care team are uniquely qualified to contribute to the meaningful design of potentially effective accommodations. This active involvement might even influence other forms of reported workplace discrimination (eg, terms of employment, relations). Reasonable accommodations typically involve modest costs (88). Also, both large and small businesses have reported direct benefits from workplace accommodations for many types of disabled workers, including: retention of qualified employees, increased employee productivity, avoidance of employee replacement costs, improved relations with employee, and even improved



company morale and productivity (125). The direct effect of specific accommodations on work outcomes in those with a history of cancer is currently unknown. If productivity remains modest or continues to decline after a legitimate effort to accommodate, it is important to remember that employers are not expected or required to lower productivity standards for persons with disabilities.

Pre Amendments Act, ADA allegations related to reasonable accommodation were found to be meritorious in those with a history of cancer more often than any other chronic illness group (97), indicating a disproportionate presence of independently verified discrimination in this area. Although the legal support in this domain is apparent, the current findings indicate that the prevalence of these allegations persists despite changes in the law. Current workplace practices are simply not meeting the needs of some employees affected by cancer. Oncology providers can use their knowledge related to a patient's current clinical picture and expected long-term and late effects to provide information for more personalized accommodations. If communicated to the correct stakeholders, this information can assist in a viable return to a competitive level of productivity. Research on how best to involve the oncology team to achieve optimal work outcomes needs to be conducted.

Accommodations that are acceptable to both employee and employer can take time to develop and implement (47; 89), and therefore referral may be necessary. The status quo regarding cancer and work is insufficient to meet the needs of certain employees and employers despite the ADA Amendments Act. Patients would benefit from proactive involvement of the oncology care team.

## **CHAPTER 3: Study 2—Cancer, comorbidity and workplace discrimination: The US experience**

### **INTRODUCTION**

Cancer survivors who desire to return to work or remain employed experience a range of workplace challenges in many countries around the globe (95; 100; 131). They face barriers including physical (e.g., pain, fatigue, cognitive limitations) and emotional (e.g., anxiety and depression) acute, long-term, and late effects, which can significantly impact their work ability and sustainability (29; 99). Compared to their non-cancer counterparts, cancer survivors of working age report poorer overall health (22) and miss more work days due to illness/injury (149). Working age cancer survivors also report a higher prevalence of one or more comorbid health conditions, compared to working age individuals without a history of cancer (50). These comorbid conditions can create barriers in the workplace above and beyond that typically faced by cancer survivors. The presence of comorbidities among cancer survivors has been associated with a reduced likelihood of employment (30). Additionally, in those who are employed comorbidities have been associated with lower levels of perceived work ability (34). Despite these challenges, many cancer survivors with additional health problems desire or need to work. Work often provides needed income, as well as desired social contact, a source of identity, and a sense of normalcy for individuals dealing with illnesses, such as cancer (118).

Work and cancer models reflect this relationship between medical factors (e.g., comorbid medical diseases, bodily challenges, psychosocial difficulties) and work outcomes (e.g., ability, sustainability, sick leave) (40; 99). They also suggest that certain workplace factors (e.g., type of work, work demands, work environment, and employer

accommodation) can be related to these work outcomes (e.g., ability, sustainability, sick leave) (40; 99). Subsequent research using a heterogeneous group of US cancer survivors to examine one such model provided support for this assumption (40). Findings from the study indicated that certain workplace problems (i.e., treated poorly, passed over for promotion, failure to accommodate, and discrimination) were related to lower levels of perceived work ability (i.e., self-ratings of "whether cancer survivors were unable to work full time, unable to work the same as before cancer, or unable to work at all";  $B = 0.22, p = 0.05$ ) (106). In those with physical illness in general, work ability and sustainability are also related to quality of working life, such as climate and company policies and procedures (26).

Advocates for those with cancer have emphasized the important role of legal policy to address and/or prevent cancer-related discrimination in the workplace. Much of the recent global policy efforts are promulgated by the UN Convention on the Rights of Persons with Disabilities, operational in 2008. This policy is consistent with various country-specific anti-discrimination efforts, including the Americans with Disabilities Act (originally signed in 1990, revised in 2009) and the European Accessibility Act (proposed in 2015 and currently under continued negotiation). Consistent with the UN Convention on the Rights of Persons with Disabilities, these policies aim to promote equal participation in society for individuals with many types of functional limitations (including those with chronic illnesses, such as cancer).

The current study focused on the recently revised Americans with Disabilities Act (i.e., the Americans with Disabilities Act Amendments Act). Under the original Americans with Disabilities Act, cancer survivors with comorbidities filed certain claims

(regarding terms of employment and interpersonal relations at work) at higher rates than either cancer survivors without comorbidities, or individuals with other non-cancer illnesses (39). The revised act was intended to be more responsive to the episodic nature of complex health problems than the original act (9). Therefore, it was assumed cancer survivors with additional health problems would receive equal protection to cancer survivors without comorbidities under the revised policy. Given the increasingly global nature of work and emphasis on inclusivity of those with chronic illness, these results can have clinical, practice, and policy-level implications for many.

## **METHOD**

### **Data Source and Sample**

A subset of the US Equal Employment Opportunity Commission (the agency responsible for the regulation of workplace discrimination policy in US workplaces with 15 or more employees) Integrated Mission System data, maintained by the National Equal Employment Opportunity Commission Americans with Disability Act Research Project, was used for all analyses. Records were supplied in a Microsoft Access file and were converted to IBM SPSS Statistics Version 22 (64) for analysis. The data set included information on cancer history (i.e., yes or no), comorbid condition(s), demographic characteristics (sex, age, race), employer variation (type and size), year the claim was filed, specific claim type (hiring, reasonable accommodation, relations, terms of employment, and termination), and merit of claim (merit or no merit, as per the Equal Employment Opportunity Commission or federal courts). Selected cases included individuals ages 18-64, with history of cancer, and minimum of one claim filed from 2009 through 2011, under the revised act.

## Data Analysis

The independent variable for all primary analyses was presence of comorbid condition(s) (dichotomous; 0, 1+). Primary outcome variables included: third party determination of merit of the claim filed (dichotomous; merit, no merit) and actual type of discrimination claim (categorical). Since claim type categories were not mutually exclusive, each claim type, including hiring, reasonable accommodation, relations, terms of employment, and termination-related, was analyzed separately as a dichotomous variable (i.e., filed or not filed).

Sex (dichotomous) and age (continuous), as well as employer region (categorical) and size (categorical) were considered for inclusion as control variables based on their relationship with allegation type demonstrated in the literature. Specifically, (1) age: compared to younger workers (< 55 years old), older workers ( $\geq 55$  years old) filed fewer allegations related to involuntary termination, and greater allegations related to other claim types (e.g., terms and conditions, undesirable work assignments, involuntary retirement) (20); (2) age and sex: Termination claims were more likely to be filed by younger (15-34 years old), male claimants (84); and (3) employer type and size: Hiring allegations (vs. non-hiring) were more likely to be filed in small employers and employers located in the Western region of the US and less likely to be filed in medium sized employers and employers from certain other regions (i.e., Midwest, US Territories, and Northeast) (98). Additionally, because a strong relationship has been demonstrated between allegation type and merit outcome (31), allegation type, as well as these demographic and employer variables, were considered for inclusion as control variables in the merit analysis.

A priori analyses included six separate multivariable logistic regression analyses. Five multivariable logistic regression analyses were used to evaluate the association between presence of comorbid conditions (independent variable, or IV) and claim type (dependent variable, or DV; separate regressions for each type). The additional multivariable logistic regression was conducted to investigate the relationship between presence of comorbid conditions (IV) and merit of claims filed (DV). All potential control variables were evaluated for between group differences to determine the appropriateness of their inclusion. Based on the recommendation of Becker et al (7), logistic regression models were also evaluated both with and without potential control variables to determine the contribution of these variables to the models.

## **RESULTS**

### **Sample**

The present analyses were restricted to individuals aged 18-64 (consistent with the typical US working age range). Individuals for whom age was not reported were excluded from the data set. Variables with sufficient data (i.e., < 10% missing per group) were retained. Race and employer industry had  $\geq 10\%$  of data missing per group and, therefore, were not included in the analyses. Analyses included claimants with full sets of data on retained variables. Ten percent of claimants ( $n = 147$ ) were excluded from the analyses due to incomplete data. There were no significant differences on demographic (age, sex) or employer (region, size) characteristics between the retained and removed cases.

The final sample consisted of 1,291 cancer survivors who were primarily women (65%), a mean of 50 years old (standard deviation [SD] = 9.24; range = 22-64). Almost

half of them (46%) filed claims against employers with 501 or more employees and the largest portion of employers were from the Southeast (25%) and Midwest (22%) regions of the US. Cancer survivors with and without comorbid conditions did not significantly differ on any of these variables (Table 1). Of the cancer survivor claimants with comorbidities, approximately 50% of comorbid conditions fell into the category of ‘disabled undefined’. Of those that were specified, the most common conditions included depression (14%), diabetes (9%), orthopedic/back injuries (8%), and cardiovascular diseases (8%). See Table 2 for detail.

### **Claim and Merit Characteristics**

Claim and merit characteristics are indicated in Table 3. Claim categories were not mutually exclusive. The majority of claimants (70%) filed termination-related claims. Very few claimants (6%) filed claims related to hiring. Each of the other claim types (i.e., terms of employment, relations, and reasonable accommodations) was filed by approximately 30% of claimants. Twenty-nine percent of individuals filed claims that were determined to have merit, as per a third-party evaluation completed by the Equal Employment Opportunity Commission or federal courts.

### **Primary Analyses: Claim Type**

Odds ratios from claim type analyses including and excluding the potential control variables differed by  $< 0.1$ , indicating that the impact of the control variables was negligible (7). Based on this finding, as well as a lack of significant between group differences for these variables, only the results of analyses without control variables were reported. Cancer survivors with comorbid condition(s) were more likely to file a discrimination claim related to the terms of their employment (i.e., terms of

employment/conditions, promotion, wages, benefits, benefits—insurance, union representation, benefits—retirement/pension, waivers, exclusion, seniority, severance pay denied, maternity, tenure, posting notices, segregated facilities, and segregated locals), compared to those without any comorbid conditions (OR = 1.37, 95% CI = 1.04-1.80). There was no relationship between presence of comorbid conditions and any other claim types (i.e., hiring, reasonable accommodation, relations, or termination). See Table 4 for additional details.

### **Primary Analyses: Merit**

Odds ratios for the merit analyses including and excluding the potential control variables differed by only a negligible amount ( $< 0.1$ ). Based on this finding, as well as a lack of significant between group differences for age, sex, employer type, and employer size, only the results of the analysis without control variables was reported. There was no relationship between presence of comorbid conditions and merit. See Table 4 for additional details.

### **Post-Hoc Analyses: Merit**

Given the significant relationship between terms of employment claims and comorbid conditions, a post-hoc multivariate logistic regression was conducted. This analysis evaluated the main effect of terms of employment and an interaction effect of terms of employment by presence of comorbid condition. There was a significant relationship between terms of employment and merit (OR = 1.44, 95% CI = 1.06-1.96), indicating that terms of employment claims were more likely to be ruled in favor of cancer survivors (versus employers). There was no relationship between the interaction



term and merit indicating that, for claims involving terms of employment, comorbidity is not related to merit. See Table 5 for additional details.

## **DISCUSSION**

This study examined how cancer survivors with comorbidities fare under a revised work discrimination policy that provides greater sensitivity to the actual nature of chronic health conditions. Despite this new policy, claimants with a history of cancer and other chronic health problems reported greater discrimination at work in their terms of employment (e.g., promotion, terms and conditions, wages, benefits), than cancer survivor claimants without comorbid conditions. Cancer survivor claimants with and without comorbidities did file other workplace discrimination claims at equal rates in areas such as hiring, relations, reasonable accommodations, and termination. Additionally, claims were ruled in favor of cancer survivors with and without comorbidities at equal rates, regardless of the type of allegation. Notably, cancer survivors filing terms of employment claims were more likely to have these claims ruled in their favor (versus employers), regardless of comorbidity status.

Results of the present study suggest that cancer survivors with comorbidities fare differently in certain areas under the revised and more accurate policy, than under the original policy. Specifically, prior research on the original act reported that cancer survivors with comorbidities filed claims involving relations and terms of employment at higher rates than cancer survivors without these other conditions (39). The present study suggests that, under the revised act, cancer survivor claimants with comorbidities are faring better in the area of relations, but not in the area of terms of employment. Likelihood of merit determination of a claim has not been evaluated in cancer survivors

with comorbidities under the original act. However, under the revised act, cancers survivors with and without comorbidities appear to be receiving equal legal protection, as evidenced by equivalent rates of merit.

Why might the presence of comorbidity differentially impact terms of employment discrimination, despite what appears to be equivalent legal protections under the revised policy? It is well-known that cancer survivors *in general* face challenges related to certain terms of employment, including reassignment of job tasks or positions, denial of opportunities for promotion, and challenges related to health insurance and/or life insurance (increased premiums, losing coverage, denials of initiating coverage) (130). However to the authors' knowledge, other than the study on the original law (39), the impact of comorbidity on workplace discrimination in cancer survivors has not been specifically investigated. The literature on work ability can provide some insight. Adults with multimorbidity tend to have more functional challenges and higher levels of disease severity, as compared to those without multimorbidity (117). This can negatively impact work-related function. Additionally, it has been reported that employed cancer survivors with comorbidities have a lower perceived work ability, as compared to employed cancer survivors without comorbidities (34). Importantly, these types of challenges in perceived work ability have been directly related to workplace discrimination in cancer survivors, such as being passed over for promotion (106). Based on this literature, it appears perceived work ability may play a role in the modification of terms of employment for cancer survivors with comorbidities, and vice versa. Future research should further delineate this relationship.

Perhaps the most parsimonious explanation for the present findings is related to differential expectations between employer and employee about required accommodations and productivity. This can occur when facing the challenges of managing multiple chronic health problems. Employers may rightly fear being “stuck” with someone in order to reduce the threat of legal or other disruptive actions (71). They may also worry about costs of accommodations and expected diminished productivity. These employer concerns may be based on past experience with a former employee with such a health history, or due to stigma specific to cancer (128). Employee expectations that employers have an obligation to retain them, regardless of challenges in productivity, may further exacerbate these problems. Such factors, if operational, can lead to discrepancies in the expectations of both parties involved. This may lead to an impasse in generating effective solutions, as well as denial of promotion or expected salary increases. Further research examining the specific expectations of the employer and employee and the development of more effective solutions is justified.

Another pattern that can emerge is where an employee remains at work until changes in the terms of their employment are so intolerable they simply leave the workplace. Specifically, when an employer who wishes to terminate an employee due to disability-related challenges decides to retain them, simply to avoid “legal repercussions” (71), they may ratchet down an employee’s progress in the company (e.g., deny promotion or raises, demote to an “easier” job), with the likely hope of encouraging the employee to leave on their own (128; 130). This may actually have long-term adverse consequences on the employee’s health and well-being. In this

context, it is important to recall that when filed, these “terms of employment” disputes are more likely to be determined in favor of the employee (versus employer) by third party mediators. This suggests a longer-term, more proactive approach may prove more effective for employers in terms of cost and productivity of a given worker. Future research should develop these types of approaches and evaluate their impact on employer factors (e.g., employee cost and productivity) and employee factors (e.g. health, well-being, perceived work ability).

If work is a desired outcome for the employee, it is important for the employer and employee to acknowledge when problems related to work exist and attempt to generate alternative approaches. Health care providers, such as oncologists, primary care providers, and nurse navigators, can play a critical role in the effort to address these difficulties in cancer survivors with comorbid health conditions. For example, they could inquire about the impact of cancer and comorbid condition-related symptoms on workplace function, or ask about specific problems in the workplace environment as it relates to the patient’s illnesses (e.g., perceived lack of support by employer, lower perceived work ability by employee, or problems with sustained productivity). Providers could then encourage additional symptom management options, discuss accommodations potentially acceptable to both the employer and employee (e.g., taking more frequent breaks, inquiring about a flexible work schedule), and/or refer the individual to specialist providers with expertise in the problem area (i.e., vocational counseling services, physiatrist, occupational therapist, physical therapist, psychologist, social worker). If a desired goal of long-term survivorship is engagement in work, these cancer survivors do not need to be silently sidelined or prevented access to a productive work life.

It should be noted that these results are based on those with a history of cancer who actually filed a discrimination claim. Given the employment risks and time involved in filing such a claim, the results likely reflect the most egregious cases and not cancer survivors at work in general. Providers should keep in mind that there may also be other, subtler forms of workplace discrimination that do not rise to the threshold of a formal claim, but do negatively impact the day-to-day work lives of both cancer survivors and their employers. Additionally, given that 50% of the comorbid conditions in the present study were "undefined", it is possible that more detail about these comorbidities would provide greater insight into the differential experience of these cancer survivors and how to best help them manage work-related challenges. Lastly, in generalizing these findings to other countries, variations in cultural, workplace policy and practice, health care, and comorbid health conditions must be acknowledged. For example, provision of health insurance continues to be a “term of employment” specific to the US. While this variation exists, challenges related to work and cancer are reported throughout the world (95; 100; 131). Despite these weaknesses, the present study had several strengths. It utilized a database which included the entire population of claims actually filed by working age cancer survivors (18-64) in the US from 2009-2011. Additionally, the data consisted of official legal claims and their outcomes, as compared to subjective self-report data.

## **CONCLUSION**

The conceptualization of chronic illnesses under the revised Americans with Disabilities Act is more consistent with the scientific literature related to chronic illness. The goal of this study was to determine whether cancer survivor claimants with comorbid

health problems report greater workplace discrimination than their non-comorbidity counterparts under this revised policy. Findings indicated that, despite the development and implementation of more progressive workplace policies, terms of employment challenges for US cancer survivors with comorbidities continue to exist above and beyond that of cancer survivors without these health conditions. Additionally, the revised US law under investigation in this study shares many similarities with the UN Convention on the Rights of Persons with Disabilities, which has guided policies across 164 countries. Therefore, the present results may have implications for policy efforts in these countries, as well. The types of injustices observed in the present study can be better addressed if all key stakeholders (health care providers, cancer survivors, employers) are involved and open to evolving evidence-based alternatives.

## **CHAPTER 4: Study 3— Development of the Cancer Survivor Profile (CSPro) App: Patient and Nurse Perspectives on a New Navigation Tool**

### **INTRODUCTION**

One in eight U.S. women will be diagnosed with breast cancer in her lifetime (121). Approximately one third to one half of cancer survivors experience acute, long-term, and late effects following the completion of surgery, radiation, and/or chemotherapy (139; 152), which can negatively impact health, function, and well-being (30; 76; 127). Common challenges include medical (e.g., cardiac, second tumor, cancer recurrence, pain)(11; 15; 46; 81; 144), psychosocial (e.g., depression, anxiety, fear of recurrence) (60; 75; 77; 120; 122; 147), functional (e.g., work, cognitive, interpersonal, financial, sexual) (4; 21; 34; 43; 67; 78; 83; 113; 128; 142; 150; 153), and lifestyle concerns (e.g., diet, weight, inactivity) (8; 115; 116). Breast cancer survivors (BCS) can experience difficulties with healthcare seeking skills, as well, such as accessing and understanding health information (42; 51; 119), effectively communicating with healthcare provider (19; 41; 111), and feeling competent in managing one's own health (44; 54; 74). BCS report unmet needs in these areas, as well as gaps in consistent post-treatment screening, interdisciplinary approaches to evaluation, long-term follow-up, and/or provision of self-management strategies (17; 45).

Clinical communication tools, such as treatment summaries and Survivorship Care Plans (SCPs), have been proposed to bridge the transition from cancer patient to cancer survivor (65). Treatment summaries and SCPs provide information on potential long-term and late medical effects, surveillance recommendations, and briefly cover psychosocial and behavioral health needs (35). These clinical tools are actively being implemented and evaluated for clinical utility (92; 102). Over the past decade, because

of their face validity, support by patients, and modest evidence of their utility, many organizations and advocacy groups have recommended treatment summaries and SCPs as tools to improve quality care for cancer survivors (94). In all cases, recommendations highlight the importance of evidence-based communication and follow-up care.

While SCPs and treatment summaries provide essential cancer treatment-related information, their utility in the facilitation of clinical care and self-management in cancer survivors remains to be determined (14; 92). Many cancer survivors continue to report problems with quality patient-provider communications related to medical care after active cancer treatment, and many do not receive any information related to symptoms, long-term or late effects, or lifestyle, emotional, or social concerns (19). This suggests the need for more comprehensive, efficient communication approaches to assist cancer survivors in their efforts to remain healthy and improve function. Discrepancies between supply and demand of oncology professionals, projected long into the future (11; 38), also indicates the need for more efficient types of evaluation and communication tools.

Studies investigating communication tools such as conventionally printed documents, internet-based approaches, and wireless technology (e.g., applications [apps] on smartphones), have shown that these formats are associated with improvements in knowledge, patient-provider communication, and decision making (41). A review of technology-based approaches used to deliver follow-up care to cancer survivors (e.g., simple standardized calls delivered by specialist nurses, remote symptom monitoring using a smartphone or personal digital assistant [PDA], automated voice-activated telephone response system, and even a computer-based approach that assists in decision



making) indicated that these systems are safe and acceptable to patients, and do not impair their quality of life or increase their distress (28).

In order to optimize today's healthcare delivery, especially for complex chronic illnesses, collaboration among providers and patients is imperative (23; 145). When this kind of teamwork is executed successfully, treatment outcomes can often be improved, particularly in the case of prepared, proactive providers working with informed, activated patients (13; 23). For example, when this type of health care model is applied to individuals with diabetes, recommended eye and foot examinations and disease-specific knowledge are improved (53). Effective management of patients with chronic illness, including survivors of a cancer diagnosis and treatment, often requires providers to take on more of a coaching role, promoting self-management and problem solving in their patients (61; 96; 146); information technology (IT) can facilitate this type of approach. A review of patient empowerment and IT, conducted to inform the development of new IT approaches for cancer survivors, concluded IT approaches that enhance empowerment improve the patient's perceptions of themselves as: autonomous, respected, knowledgeable, useful, skilled in psychosocial and behavioral matters, and supported by family and friends (49). Groen et al (49) propose that these attributes be considered when creating IT approaches to be used by cancer survivors when patient empowerment is a goal.

The present study examined BCS and nurse case managers views about the components of a new IT approach to potentially compliment SCPs: the Cancer Survivor Profile (CSPro) app. The CSPro app was created to identify unmet needs and facilitate self-management following active oncological treatment for breast cancer. It was

designed to utilize the CSPro-Breast (135) to efficiently deliver personalized information related to unmet needs and provide corresponding online resources. The CSPro app was evaluated within a breast cancer clinic during a survivorship visit. Obtaining feedback on each of the CSPro app elements, within the environment for which the app was designed, provides useful information for further development of this clinical tool (155).

## **METHODS**

### **Development of CSPro App**

The CSPro app was developed as a communication tool to assist in the transition from cancer patient to cancer survivor. It utilizes an evaluation tool, the CSPro-Breast (135), to provide clinically meaningful information and identify and manage common unmet needs following active treatment for breast cancer. The CSPro-Breast is based on epidemiological and qualitative research on the unmet needs of BCS following active treatment. It was generated primarily using existing, well-developed measures of patient-reported outcomes of post-treatment symptom burden, function, health behavior, health care seeking skills, and a few investigator-generated measures when an existing measure was not available (135). The CSPro-Breast requires approximately 15 to 20 minutes to complete. The CSPro app consists of five major elements<sup>1</sup>:

- 1. Survey Delivery**

Administers the CSPro-Breast and Social Desirability Questionnaire-Short Form (to adjust for the tendency to provide socially acceptable responses; see #4 below), providing no more than 6 questions per page and a displaying a time bar to track the patient's progress throughout the survey (see Figure 1 for sample questions);

<sup>1</sup>The CSPro-Breast survey is in the public domain. However, the current version of the app was developed using the proprietary software of MicroStrategy (Tysons Corner, Virginia). The generic processes used for survey administration, calculation of scores, profile output, and provision of problem-specific resources are in the public domain. The authors do not benefit financially from the use of this app.

## 2. Calculate Raw Scores

Instantaneously calculates raw scores for each of the 18 psychometrically determined independent problem areas (135), including: symptom burden (anxiety, depressive symptoms, fatigue, body image difficulties, fear of recurrence, pain), functional difficulties (cognitive, sleep, sexual, social), health behaviors (physical activity, healthy diet, unhealthy diet), health care seeking skills (health care competence, patient-provider communication, ability to access and understand health information), and financial strain related to cancer;

## 3. Standardize Scores

Calculates t-scores for each subscale, adjusting select subscales for social desirability based on correlations demonstrated in the development study (135)

*Scales adjusted for social desirability* include fear of recurrence, body image, fatigue, depressive symptoms, anxiety, social relationships, sleep, cognitive function, unhealthy diet, healthcare confidence, and patient-provider communication. Calculation inputs include three fixed numbers based on the reference group (N = 400) in the original development study (135) (the slope-B1, intercept-B0, and mean squared error-MSE), and two numbers based on survey input from the current BCS user (social desirability raw score-X and CSPro-Breast raw score for a given scale-Y). The following series of calculations is used to generate the t-scores adjusted for social desirability:

$$\text{Predicted Value } (\hat{y}) = B0 + B1 * X$$

$$\text{Raw residual } e = y - \hat{y}$$

$$\text{Standardize Residual } Z = \text{Raw residual } e / \sqrt{\text{MSE}}$$

$$\text{t-score} = (10 * \text{Standardize Residual } Z) + 50$$

*Scales not adjusted for social desirability* include pain, work, sexual function, healthy diet, physical activity, health information, and financial strain. Calculation inputs include two fixed numbers based on the reference group (N = 400) in the original development study (135) (the mean-M and standard deviation-SD), and two numbers based on survey input from the current BCS user (CSPro-Breast raw score for a given scale). The following series of calculations are used to generate t-scores for these scales:

$$Z = (\text{Total raw score} - M) / (SD)$$

$$\text{t-score} = (\text{z-score} * 10) + 50$$

## 4. Generate Profile

Generates a user-friendly personalized profile of the 18 different problem areas. The graph uses color-coded bars based on t-scores (mean = 50, SD = 10). The color-coded classifications include red (areas to "act" on, t = 61+, or  $\geq 1$  standard deviations above the mean), yellow (areas to "watch",

t = 41-60, or within 1 standard deviation of the mean), and green (areas to "maintain", t= 0-40, or  $\geq 1$  standard deviation below the mean). See Figure 2.

**5. Generate Corresponding Resources Links**

Provide problem-specific links to online resources (i.e., videos, websites, social media, podcasts, and booklets), corresponding to elevated areas (i.e., red areas). See Figure 2.

Resources were primarily collected through a comprehensive search of websites for cancer survivorship organizations and scientifically based websites (e.g., National Cancer Institute, American Cancer Society, Macmillan Cancer Support, Journey Forward, Dana Farber Cancer Institute). All resources were reviewed by investigators (MF and AG) and included based on appropriateness for the patient population, as well as consistency with the research literature, clinical guidelines, and/or clinical experience working with this population.

The CSPro app offers an efficient way to obtain information on 18 areas, not presently covered in detail in current SCPs (92; 135). It provides a statistically valid (construct, content, and discriminative) and reliable (inter-item and test-retest) measure of the 18 different challenges and is related to perceived levels of health related quality of life (135). These are all characteristics expected in a quality patient-reported measurement tool (132).

Additionally, the standardization of scores provides the opportunity for the individual BCS to observe her scores on 18 potential problem areas relative to a group of BCS living a median of 2 years post active treatment. This allows the new BCS to observe her current symptoms, function, health behavior, healthcare seeking skills, and financial strain relative to BCS further out from active treatment. This represents a unique aspect of the CSPro, but ideally requires a fully representative sample of BCS, reflective of the BCS population. Currently, the normative sample is based on the sample (N= 400) obtained in Todd et al (135). The present study was an evaluation of BCS perspectives

on the five components of the iOS (e.g., iPad) version of the CSPro app and related procedures (i.e., review of app output with nurse navigator and brief instruction in problem solving related to problem areas identified) in a breast cancer clinic setting.

### **Perceptions of CSPro App**

Perceptions of the CSPro app were evaluated using a mixed methods design. Data were collected at two time points: clinic appointment and follow-up phone interview (approximately 2 weeks later). During the clinic appointment, quantitative and qualitative data were collected through a series of online structured surveys, inquiring about perceptions of each app component. The quantitative probes provided a structured means of obtaining perceptions of app components, while the qualitative questions allowed for elaboration on quantitative responses and provision of any additional feedback. The follow-up phone call consisted of a semi-structured interview, which offered the opportunity for developers to obtain perceptions of the app components in a BCS' own words, following the opportunity for home use. Appendix 1 provides the questions used in the follow-up phone call.

### ***Participants***

Female military health care (TriCare) beneficiaries who recently completed active treatment for breast cancer were recruited. Inclusion criteria were: ages 20 to 78, stages I-III breast cancer, completion of active treatment (i.e., surgery, chemotherapy and/or radiation) within the past 2 years, access to a home computer and internet, and computer and internet literacy sufficient to access the individualized profile and problem-specific resource links. Individuals were excluded if they reported a history of another cancer other than this first occurrence of breast cancer (except for stage 1 and 2 non-

melanoma skin cancer), or history of serious mental illness (i.e., schizophrenia, other psychotic disorders, bipolar disorders, major depressive disorder), post-traumatic stress disorder, or traumatic brain injury. The criteria used for inclusion/exclusion were largely consistent with that used in the original normative study (135). Approximately half (51%) of individuals in the reference sample (N = 400) completed active treatment within the past 2 years (135).

### ***Recruitment***

All recruitment and study procedures were approved by the Institutional Review Boards at Walter Reed National Military Medical Center (WRNMMC) and Uniformed Services University of the Health Sciences (USUHS). At the breast care center, each breast cancer patient works with a specific nurse navigator from diagnosis through treatment, and has a survivorship appointment with the nurse navigator following completion of active treatment. In the current study, potential participants (BCS) were informed of the study by their nurse navigator during a routine survivorship appointment scheduling phone call. If they expressed interest, these BCS were subsequently screened by research assistants. The participants used in the present study included a convenience sample of BCS following active treatment, and seen in the breast care center.

Recruitment continued until no new feedback related to the CSPro app elements or the process of delivery was provided (i.e., the point of saturation), as determined by investigators (MF and AG).

### ***Procedure***

Research assistants arranged to meet with qualified participants at the Breast Care Center. After participants provided informed consent, they completed the following

surveys on an iPad: (1) a demographic and health information questionnaire, (2) the CSPro-Breast survey and the brief social desirability measure, and (3) a questionnaire on their impression of the CSPro-Breast survey content (i.e., comprehensiveness of problem area coverage), length (i.e., time burden of survey length) and app-based presentation (i.e., layout, number of questions per page, etc.), including a combination of Likert scale (e.g., extent to which you agree or disagree, where 0 = not at all, 10 = completely agree) and open-ended questions. All Likert scales ranged from 0 – 10. For ease of interpretation, Likert scale responses were transformed in to dichotomous variables where 0-5 = No and 6-10 = Yes.

Participants then met with their nurse navigator to complete usual care procedures, including reviewing surveillance calendar, treatment summary, and SCP, and providing Facing Forward booklet covering general survivorship guidance (<https://www.cancer.gov/publications/patient-education/life-after-treatment.pdf>), as well as intervention procedures. To duplicate the proposed use of the CSPro in the clinic, nurse navigators: (1) reviewed the patient's survivorship profile (i.e., graphic display), (2) explained the meaning of the different color-coded areas on the graph, (3) discussed "act" (red) areas of the profile (covering a max of three, with a focus on red areas, including distressing yellow areas only if there were less than three red areas (24)), (4) offered corresponding recommendations and referrals, as needed per clinical judgment, and (5) provided brief training in a problem solving approach targeting the identified problem areas.

Following the appointment with their nurse navigator, participants met with research assistants to: (1) obtain a hard copy of profile (printed color copy) and electronic

copy of profile and personalized problem-specific resources for all red areas (i.e., flash file provided on a 16 GB flash drive); (2) receive instructions on how to access profile and online resources using flash drive, including a demonstration on a laptop (PC) not connected to any Department of Defense [DoD] internal network; and (3) complete questionnaires on the perception of the CSPro graphic display in terms of clarity of display, degree to which the graphic display and discussion facilitated understanding of specific problem areas and potential ways to address them, and value of providing problem-specific resources. Determination of this information was based upon both Likert scales and open-ended questions.

The researchers selected the flash drive medium over an electronic communication-based medium (e.g., email or online portal) because of restricted access to secure health record-based messaging within the military health facility. Due to DoD restrictions regarding the use of a flash drive on any DoD device, explicit reminders were provided-including verbal and written (on the flash drive). Following the clinic appointment, participants were encouraged to call research staff or their nurse to address any questions related to interpretation or access of the CSPro graphic display, resources, or related referrals. All structured surveys were completed on an iPad. The CSPro-Breast survey and the brief social desirability measure were administered using the iPad-based CSPro app. All other questionnaires were administered using SurveyMonkey (<https://www.surveymonkey.com/>; a HIPAA compliant, secure, online survey tool).

Participants were also asked to take part in a 10-20 minute, semi-structured phone interview with a research assistant 1 to 2 weeks after the completion of their clinic appointment. Questions covered their experience with the CSPro app and resources since



the clinic appointment (i.e., Have they thought about them? Accessed them? Shared them with others? Do they expect to? etc.), as well as their use of clinic referrals (if applicable) and any general feedback. Specific questions are provided in Appendix 1. This query method provided the opportunity to obtain more open-ended detail related to each of the CSPro elements covered during the visit. These interviews were recorded and transcribed (except for one, which was not recorded due to a technical difficulty with the recording device; feedback for this call was solely based on research assistant notes taken during the call). Transcripts were reviewed by investigators (authors AG, MF, LM, and CM) and themes were identified and discussed as a group. Two investigators (MF and AG) then independently classified feedback into theme categories. Any discrepancies in this classification were discussed by the investigators, and a final determination was agreed upon.

### **Nurse Navigator Feedback**

As part of the CSPro app development and testing, three nurse navigators involved in the study also provided informal guidance and feedback to investigators regarding the app (e.g., ease of interpreting graphic display, utility as a communication tool). These nurse navigators had a range of 10 to 17 years of experience as breast cancer oncology nurses.

## **RESULTS**

### **Participants**

#### ***Demographic Information***

Participants included eleven female military health care beneficiaries. See Table 1 for more detail. While most of these individuals were between the ages of 35 and 64,

highly educated, Caucasian, and married, with a combined household income of \$80 000 or more, other age groups (i.e., 65-74), education levels (i.e., high school diploma, associate's degree), races (i.e., Asian, African American), and marital statuses (i.e., divorced) were also included.

### ***Medical History***

Table 1 provides specific information on treatment exposures and menopausal status. The majority of participants were diagnosed with stage 1 or 2 breast cancer and received varying combinations of surgery, radiation, chemotherapy, and/or hormonal therapy.

### **BCS Perceptions—Clinic Appointment**

#### ***CSPro-Breast Survey Delivered on App***

Figure 1 provides a screen shot of the app-based CSPro-Breast survey. The majority of BCS (91%) perceived the survey as taking "just the right amount" of time to complete and "covering major problems experienced by BCS". Detailed ratings of all features of the survey can be found in Table 2.

#### ***CSPro Graphic Output***

Figure 2 is a screen shot of graphic output provided to BCS and nurse navigators, including an illustration of the problem-specific resources generated for scores in the red (or "act") range. Specific ratings of BCS' perception of each major feature of the graphic display and related recommended resources are provided in Table 2. Overall, the graphic profile was viewed positively, with suggestions for improvement provided across select areas.

Likert ratings indicated that the majority of BCS (91%) found the graphic profile represented each of the 18 problem areas in an understandable manner and all BCS thought that it was a useful communication tool to discuss problem areas with their nurse. No BCS endorsed the statement that it “seemed like a waste of time—I knew this already”. Ratings indicated that 82% of BCS thought the graph could “stand on its own with little explanation”. It was also observed that the majority of scores (bars on the graph) fell into the yellow or “watch” category. Patients often wanted to discuss these yellow areas with the nurse navigator and requested additional resources for these areas, as well. While most BCS (89-91%) thought the problem-specific resources would be helpful, some were not certain. Table 2 provides detailed information on BCS perspectives.

### ***Brief Training in Problem Solving***

Detailed ratings of BCS' perceptions of the brief coaching in a problem-solving approach, targeting their CSPro app-identified problem areas, are presented in Table 2. Responses indicate that, the majority of BCS were confident that the approach could help them to “generate new ideas on how best follow through efforts to improve problems that were identified by the CSPro” and that they would use these strategies in the future.

### **BCS Perceptions—Follow-Up Interviews**

Phone-based follow-up using semi-structured interviews (10-20 minutes) were conducted an average of 16 days post-clinic appointment (range: 7-30 days). All eleven BCS were interviewed related to their experiences using the CSPro output (i.e., profile and online resources) after the appointment. Common themes and exemplary quotes are noted below. They are divided in to two categories: content and use.

## ***Feedback on Content***

### *1. Additional Information Needed*

...I think...that I needed a little bit more information on what some of the numbers mean...I think, you know, there wasn't- I guess maybe there just wasn't enough explanation as to what I'm supposed to do with this graph...

...How credible are all of these [resource] links? Who's the authority on it?...And that's probably some of my resistance or hesitance to dive into it...

### *2. Profile Layout Helpful, But Could Be Better*

...Well, it kind of helped to lie out. I never thought of lying out...I don't think it was confusing...you know I'm a visual person...I like the questions to get my mind thinking. Where my stressors are where my good points are. I have to see it and it's good. I like it when you guys show the graph, I say "oh my God this is neat."...And its colorful!"

...I know you have everything up there...[but] I think the things people really want to see, I know I did, [are] not the ones [that were] borderline, but the ones that were green and I was good to go and the ones that are red that I really need to work on.

### *3. Experienced Information Overload with Online Resources*

...it is information overload and...[it] probably depends on the person and then when they are in the process whether or not they're ready to...utilize that information...I just think there's a lot of information.

### *4. Prefer Another Format*

...You know it's good to have something you can refer to. And honestly, I am a paper person so having the hard copy, to me, is better...I generally print things I see on the computer, I print and look at them...I guess I'm old school and you know that's how I'd rather...look at things on paper...

I can access them [the resources], but have not had time to look and read anything...computer is not good after a day of work...tablet would be helpful.

## ***Feedback on Use***

### *1. Beneficial to Share Profile with Others*

...Just in sharing it [the profile] with my husband...I was able to discuss it briefly with him...Probably about a handful of times...In just having conversations with

family...showing it to my husband and my mom...it was something concrete that I could sort of point to that identified areas of further exploration...

...I was able to talk about this [the profile]...with my behavioral health [provider]...And my social worker ..So I was able to talk about it and say hey this is the- study that I was in and this is the results. And the two bars of the graph- the red bars I believe was my- two things I need to work on.... Work and... pain...So yes- I had talked about this with- well I had talked about it with my nurse case manager...This helped me remember it...It helps to review it with other people...

I talked about it [the profile] with my family a little bit... with my mom and my mother-in-law...Sometimes I just don't know what to say to them...sometimes I just don't have the right words because sometimes my brain is just...it's still cloudy...putting thoughts and complete sentences together about stuff, so it was really easy to say look at this... it really helped me especially with them because they ask a lot of questions.

I have not [shown it to anyone yet] Possibly [in the future]...I have a couple of breast cancer survivors that I could share with. They are close enough that I talk to from time to time. They might find it interesting, because I don't know that they received that kind of reference themselves.

## *2. Profile Beneficial to Care*

Yes, absolutely [useful to have this information]...Just in thinking about my post treatment plan, which is something I think about frequently. It's been a part of that process.

There's things I try to...look at...with my...behavioral health doctor, talking about it takes on a whole lot and so you know just organizing to help me start trying to get back into the world... Healthy and normal again in those three areas... I...think...leaving here...when I looked at the graph...yeah.... Yeah, yeah- I think it's useful. I think it's something that needs to be...given...post...survivorship.

I think about that kind of stuff all the time, I did that beforehand though so...I don't know that the intervention actually made me think more or less about any of my issues...I don't think that having the graph was...for me personally...I don't think it was as pertinent I guess...I mean...nothing showed up on there that I thought 'Oh wow I guess I have a problem with this or that' or you know that I didn't already know...

## *3. Online Resources Not Accessed*

...I haven't done much with it... you know so a lot of things had to do with...nutrition and...exercise so...basically I would think that I need to do

something. But honestly I haven't done anything...it [the profile] is definitely useful. I just haven't done anything, that's the only problem...in fact we discussed that when we were discussing the whole profile anyway... I need to do something...it's not about access, it's really about...my workload, and then after work I just want to relax...It's...my lifestyle essentially. It's like the work and then home life and I just haven't done anything...it's just me.

No...it's not at the forefront of my mind, we're getting ready to go on vacation and a thousand things are going on in life...it came home in a nice folder and it's...I did clean off the counter yesterday.... It's sitting there. I know where it is, it's not lost... I'm not just going to throw it away or get rid of it because I do think that I will have use for it.

...I think...there's going to...come a point in time where it's going to be even more useful and I'll be able to reference it ... When I decide to take time for myself. I know that the information is there whether it's at two o'clock in the morning or...it's one in the afternoon. That's kind of the nice thing I have in my head, like when I'm- potentially going to use the information.

The intent of the interview was to identify areas that could be feasibly improved in the actual clinical setting of a breast cancer clinic in a large tertiary care hospital. As can be seen from the quotes, there were areas that required change prior to our pilot trial to determine actual feasibility and to obtain a general idea of potential outcomes. Changes related to concerns are listed in Table 3.

### **Nurse Navigator Feedback**

Informal feedback on the rationale for the CSPro and clarity and clinical utility of the graphic output was provided during weekly meetings between investigators and nurse navigators, across seven months. Each nurse navigator indicated the CSPro app rationale was clear, and that the graphic output provided understandable and clinically useful patient information. The nurse navigators also noted that the process of using the CSPro facilitated communication around sensitive topics (e.g., sexual function/intimacy) that BCS are often hesitant to discuss during follow-up visits. The nurse navigators expressed that the additional time allocated to review the profile and provide feedback did lengthen

the visit. When asked whether the additional time was justified, the nurses reported that it was, but also mentioned that it was primarily up to the patients as whether the time was beneficial. The nurse navigators also expressed the importance of having a print copy of the CSPro questions for each problem area, so that they could refer to these questions when discussing an elevated scale with a patient. This was particularly important for those scales that initially "surprised" patients (i.e., scales for which patients were unclear of why they were elevated). This feedback directly informed app improvements. See Table 3 for corresponding changes.

## **DISCUSSION**

The CSPro app was positively received by BCS and nurse navigators during the initial survivorship visit in an active breast care clinic. The app's clinical utility, ease of use, and feasibility as a tool to inform BCS survivorship care was reported. BCS were able to complete the iPad-based CSPro-Breast (135) survey in about 15-20 minutes and view their profile and problem-specific resources within seconds of completing the survey. BCS perceived the problems covered by the CSPro app as comprehensive and as problems actually experienced. The majority of BCS reported that the graphic presentation of the 18 problem areas was understandable. Nurse navigators were also able to review the graphic output, readily identify certain areas of concern, and recommend personalized follow-up strategies (i.e., specific providers or clinic resources). An approach to minimize additional time in the clinical context could be the completion of the CSPro survey prior to the appointment (e.g., in the waiting room).

The present study serves as an important step in this app development process, consistent with the Yardley et al (155) framework for the development of digital health-

related behavior change interventions. The CSPro app was not designed to achieve specific behavior change, but rather to provide customized information to perhaps increase health self-efficacy, or patient activation; these outcomes have been shown to predict actual health behavior change (44; 55; 56). This goal differs from Yardley et al (155), but the elements of digital intervention evaluation still provided some guidance. The feedback collected during this stage in the app development provided useful information for the revision of the CSPro app and its delivery. Collectively, it alerted researchers for the need to modify the format, content, and process of delivering the CSPro to make the app more likely to be understood and actually used by the BCS and nurse navigator.

A potential limitation of the current evaluation is that the nurse navigator feedback was given informally in the context of using the CSPro app with patients. Although the information provided perceptions obtained directly after using the app in the clinical setting, using an unstructured format may have increased the demand bias (vs. a formal individual evaluation). Demand characteristics operating during the elicitation of feedback from nurse navigators, as well as BCS cannot be ruled out. However, every effort was made to emphasize the importance of honest answers and it was made clear that the research team would not be insulted or disappointed by negative feedback. A constraint of the present version of the CSPro app is that the data used to “normalize” scores in the original study (135) provides only limited representation of race, educational level, and age. The limited representation of race, educational level, and age in the current sample (i.e., primarily Caucasian, highly educated, with a high household income) is consistent with the reference sample from the original study (135). However,



readers should use caution in generalizing these findings to various diverse groups of BCS. Lastly, although all BCS responded to the majority of questions, as indicated in table 2 there were a few select questions for which 1-2 BCS declined to respond: 1 question (out of 9) about the CSPro-Breast survey, 3 questions (out of 4) related to about the online resources, and 1 question (out of 5) about the problem-solving training. While missing data with such a small sample may be a problem overall, given the extent of feedback on each app component provided during the follow-up phone call, the investigators believe sufficient data has been obtained to make changes in the subsequent iteration of the app.

The CSPro-Breast has strong measurement properties and its total score is related to perceived health. The CSPro app has 5 unique features: (1) assesses 18 potential problem areas in 15-20 minutes, (2) instantaneously calculates standardized scores relative to a comparison group of BCS several years post active treatment, (3) generates a personalized profile of problem areas to facilitate future medical and self-management, (4) provides a tool for communication between survivor and others (e.g., provider, spouse, family), and (5) provides a range of online resources (i.e., apps, websites, videos, podcasts, booklets) corresponding to elevated problem areas. It can assist practitioners in prioritizing problem areas in individual BCS and provide information for health and self-care options. It was designed as a customized communication tool to help guide referral to specific clinics, provide access to individualized resource information, and provide information to guide self-management efforts. However, the effects of its use in a clinical environment have yet to be determined.

As the prevalence of cancer survivors of all types continues to increase (112), it is expected that many different approaches to facilitate communication and optimize cancer survivorship will emerge (e.g., (151)). The CSPro app is one example of such a tool. Also, as SCPs evolve and data support their effectiveness in achieving certain clinical outcomes, the CSPro, or other similar tools may serve as a viable adjuncts. The CSPro can provide personalized information not fully considered in current SCPs, and in relation to survivors with more experience living as cancer survivors. The CSPro app aims to fill a critical gap in survivorship care. It is hoped that by taking a systematic, research-based development approach the CSPro will become a beneficial component of survivorship care for both survivors and providers.

## **CHAPTER 5: Discussion**

A large portion (one third to one half) of cancer survivors experience acute, long-term, and late effects of their cancer and its treatment (139; 152). Many cancer survivors also often have one or more comorbid conditions (e.g., anxiety, depression, diabetes, heart disease, arthritis) (36; 50; 81). The presence of these effects, as well as common comorbid conditions, is often negatively associated with function and overall HRQOL (63). While a range of interventions exist to target the impact of these post active treatment effects and comorbid health conditions (12; 16; 18; 66; 96; 101; 115; 126), they remain a challenge for cancer survivors (17; 18; 93). The current series of studies investigated approaches intended to assist with and/or mitigate these challenges in the two contexts in which they often present: the workplace and the healthcare setting. The goal was to evaluate the utility of current approaches to optimizing function and HRQOL in these areas, and generate clinically-relevant adjuncts to these methods, where indicated. Study 1 and 2 focused on evaluating current U.S. workplace discrimination policy protections for cancer survivors, and providing specific provider recommendations for aiding these cancer survivors with workplace challenges in the context of these policy protections. Study 3 was aimed at developing the CSPro app, an adjunct to the survivorship care plan (current standard of care), with the goal of addressing currently unmet survivorship care needs. All three studies ultimately provided insight in to current primary and possible adjunctive approaches for increased optimization of function and HRQOL in adult cancer survivors.

### **WORKPLACE**

A large subset of cancer survivors report experiencing discrimination and stigma in workplace (39; 128). Workplace discrimination can negatively affect both quality of life (e.g., physical and mental health) and work function (e.g., work ability, productivity) in cancer survivors (40; 106). Cancer survivors with comorbid conditions are particularly vulnerable to workplace challenges (30; 32; 149). The revised ADA Amendments Act was intended to provide increased access to the antidiscrimination laws for many with chronic illness, including cancer survivors. Additionally, legal opinion reports that the ADA Amendments Act has made it “easier” for cancer survivors to fall into the category of “protected” by the law under the ADA Amendments Act (59).

Findings from study 1, however, suggest that implementation of ADA Amendments Act did not improve coverage of cancer survivor claimants across most allegation types, and may have resulted in less coverage in the area of relations (e.g., poor treatment) and terms of employment. Additionally, results of study 2 indicate that, even under the Amendments Act, cancer survivor claimants with comorbidities experience disproportionate discrimination related to terms of employment (e.g., passed over for promotion), as compared to cancer survivor claimants without comorbidities. Findings of studies 1 and 2 also speak to a larger concern that, despite policy reform efforts, improved protections do not appear to have translated to actual reductions in workplace discrimination. This is evidenced by equivalent, or in some cases increased, discrimination claims filed by cancer survivors, as well as continued challenges reported by cancer survivors in this area.

## **HEALTHCARE**

Quality survivorship care following active treatment is critical in helping cancer survivors effectively manage functional and HRQOL challenges related to acute, long-term, and late effects. In recent years, the most widely adopted approach to this care has been the treatment summary and survivorship care plan (14; 72; 91; 102), but the evidence for the clinical benefits of survivorship care plans is mixed (14; 25; 72; 91), and cancer survivors continue to report unmet needs in survivorship care (69; 93; 94). The CSPro app was designed as an adjunct to the survivor care plan to address these gaps in comprehensive care (135). Based on the findings of study 3, the CSPro app assesses for and provides information about meaningful problem areas experienced during survivorship (from the perspective of breast cancer survivors), and includes problem areas that are not addressed during a typical survivorship appointment (from the perspective of nurse navigators). Study 3 also revealed that many breast cancer survivors shared their profile with others (e.g., family, other medical providers) and found it to be a useful communication tool. Study 3 provided information that assisted with app improvement, as well. This feedback allowed end-users to directly inform optimization of the app, making it more likely to be useful and effective for future use.

## **LESSONS LEARNED**

This series of studies contributed to many lessons learned for this researcher. Studies 1 and 2 provided exposure to the nuances involved when using administrative data. For example, the EEOC data set included data for all cancer survivors who filed a claim; this allowed me to evaluate an entire population of data, as compared to just using a sample. However, because these data were from an actual U.S. Government agency involved in the implementation of civil rights laws, it only included variables that were

collected for the purposes of processing allegations. This feature of the data set limited the types of research questions I could ask. Additionally, because the dataset only included cancer survivors who filed formal allegations, the entire subset of the population who experienced discrimination but did not file a claim could not be studied. This feature of the data influenced my hypotheses, and limited the conclusions I was able to draw. For example, I was not able to say what these findings indicated about the population of U.S. cancer survivors as a whole; I was only able to speak to the experience of cancer survivors who actually filed claims. This limited the applicability of these studies. Lastly, the data available only included years 2001-2011. This means that the results are not necessarily reflective of the current (2012+) pattern of claims. However, the findings do provide critical information about the immediate changes following the passage of the Amendments Act. Additionally, for study 1 data were divided in to two groups that were largely equivocal in terms of sample size, but not in time span. It is possible this distribution of time spans (2001-2008 vs. 2009-2011) could have impacted the results. A future study would ideally include equivalent time spans.

Study 3 taught me about the nuances of conducting clinical research in a military clinical oncology setting. This included the impact of typical challenges in a clinical oncology setting (e.g., frequent staff changes, ranging staff training backgrounds and level of interest in research), as well as experiences specific to the military setting (e.g., increased barriers to utilizing the hospital internet to run the app, high levels of administrative involvement and oversight, and unique features of working with a military/retiree/military dependent population). I also learned about the difficulties involved in working with a large, commercial, for-profit IT company from idea

conception through app development and refinement (e.g., challenges in translating psychological research language in to programming language).

## **IMPLICATIONS**

As a whole, this series of studies has implications across the research, clinical, and policy domains. In the area of research, findings suggest that current approaches to medical care and policy protections for cancer survivors remain insufficient to address their needs, particularly in the workplace. Study 3 suggests that adjuncts to usual care in the medical setting, such as the CSPro app, are highly desired by both patient and provider and may aid in the assessment and addressing of these challenges. Exploration in to possible contributing/explanatory factors for ongoing workplace challenges/discrimination (e.g., variation in employer-specific policies, limited dissemination of policy), investigation of potential preventative measures (e.g., increased communication, greater flexibility on the part of stakeholders, sincere attempts at reasonable accommodations), and assessment and intervention of workplace challenges by medical care team are critical next steps in this line of investigation.

The findings of the current study also have direct clinical implications. Clinically, findings suggest that both cancer survivors and medical providers are interested in approaches which help: (1) identify concerns often missed by usual care, and (2) prompt important clinical communication and individualized treatment recommendations (e.g., self-help materials, referrals, etc.) to address these areas. In the work domain specifically, findings indicate that it is critical for medical providers to assess for workplace challenges in cancer survivors, and to not assume that legal workplace discrimination protections have translated to the workplace for these individuals. Notably, while

providers are in a unique “front line” position to check in on all domains covered in the present studies, it is also not feasible to ask a single medical provider (e.g., nurse navigator, PCP, oncologist) to deliver comprehensive care on these fronts. What is clinically reasonable is for providers to assess these areas of concern, provide clinical intervention as feasible, and if not feasible, provide a referral to an appropriate provider and/or provide relevant self-help materials. This also appears to be what is desired by both cancer survivors and providers. As study 3 indicates, the CSPro app, and approaches like it, have the potential to facilitate this role. By generating approaches such as the CSPro app, which are brief enough for use in a busy clinical setting, yet sufficiently comprehensive to cover the range of relevant concerns often missed in usual care, it is possible to improve patient care while easing provider burden.

Finally, findings of the current studies have direct implications for policy, both in the U.S. and abroad. Specifically, the series of studies indicate the ongoing need to assess for and address workplace challenges within the cancer survivor population in the medical domain (e.g., as part of national and international survivorship care recommendations), in the workplace (e.g., as part of formal company policy), and within the legal system (e.g., ADA Amendments Act, or similar policies globally). The present findings also collectively demonstrate two feasible ways to do so, including approaches like the CSPro app and utilization of administrative data for evaluation of actual legal implications of policy within cancer survivor claimants.

## **STATE OF THE RESEARCH**

The field of cancer survivorship research to which these studies contribute has many strengths, as well as some inherent challenges. In 2006, cancer survivors were



considered to be “lost in transition”(65) from patient to survivor, following active treatment for cancer. At this time there were few consistent resources, and little focus on this area in research, clinical work, or policy. The National Coalition for Cancer Survivorship (NCCS) was one of the few groups pushing for change and the survivorship care plan was only recently introduced. Since that time, providers, researchers, and policy makers from many professions (medicine, nursing, psychology, social work, physical therapy, and patients themselves) have become increasingly involved in cancer survivorship research, particularly that focused on the optimization of function and HRQOL (108). These individuals contribute independently and also collaborate on studies. National groups (e.g., National Cancer Institute, National Comprehensive Cancer Network, and American Cancer Society) have begun to include specific programs in cancer survivorship, as well. Additionally, scientific journals focused specifically on cancer survivors have been launched, such as the Journal of Cancer Survivorship: Research and Practice. In more recent years, guidelines specific to optimization of HRQOL and function have been generated by major oncology-related organizations, as well (6; 16; 101; 115).

This area of research has come a long way, and is continuing on its upward trajectory. However, it continues to face several challenges. First and foremost, there are challenges in disseminating research findings and translating research in to clinical care (2). Relatedly, there continue to be interventions used clinically that are not necessarily evidence-based. For example, the survivorship care plan is a recommended, and (for certain accreditations) required, intervention to coordinate care post primary treatment for cancer, but its evidence is mixed (14; 72; 91). There is also a tendency to focus on a

specific challenge in isolation; this leaves certain areas of research siloed versus integrated, which ultimately poses a major limitation (2). Lastly, research tends to be focused on one cancer type (breast cancer) and on high income, well-educated middle-aged and older adult women. More research on other cancers, cancer survivors from other racial and ethnic backgrounds, genders, and socioeconomic statuses is needed.

With the continued collaboration and drive of cancer survivors, researchers, providers, and policy makers, cancer survivorship research is likely to become more interdisciplinary, clinically-oriented, dissemination-focused, and inclusive of unique subsections of cancer survivors. For example, in the future, I would expect to develop an intervention, such as that described in study 3, to cover multiple different types of cancer and be optimized through a range of clinical sites (VA Medical Center, Military Treatment Facility, Academic Health Center). I would also anticipate testing the impact of the app through an RCT across all sites, and generating materials to ensure the app was readily available for dissemination to clinical providers upon determination of level of empirical support.

#### **FUTURE DIRECTIONS OF THIS RESEARCHER**

I remain very interested in helping cancer survivors in the medical setting. However, my clinical training and coursework have inspired me to focus my research on program development in individuals with chronic medical conditions more broadly (e.g., cancer survivors, individuals with HIV/AIDS, diabetes, chronic pain, asthma, heart disease, etc.), and in the context of primary care. Specifically, I would like to develop programs to help veterans with chronic medical conditions optimize their function and HRQOL. The skills I learned through the current program of research apply directly to

this path of work. Moving forward, I hope to tailor the approaches described above to optimize HRQOL and function in veterans with chronic illness. For example, I could evaluate the current workplace discrimination policy protection across a range of different chronic medical conditions. I could also develop an app similar to the CSPro, but for use across several chronic medical conditions. I greatly appreciate the skills I have gained through this work, and look forward to applying them in my future work with veterans in primary care.

Study 1—Table 1. Discrimination Allegations

Categories	Allegation Types	Pre Amendments		Post Amendments	
		No.	Act %	No.	Act %
Hiring	Hiring, prohibited medical inquiry, training, job classification, qualification standards, referral, testing, apprenticeship, advertising	66	5.5	73	5.7
Terms*	Terms and conditions, promotion, wages, benefits—insurance, union representation, benefits—retirement/pension, waivers, exclusion, seniority, severance pay denied, maternity, tenure, posting notices, segregated facilities, and segregated local unions	262	21.7	353	27.3
Relations*	Harassment, discipline, constructive discharge, assignment, intimidation, references unfavorable, or breach of confidentiality	252	20.8	363	28.1
Reasonable Accommodations	Reasonable accommodations	335	27.7	389	30.1
Termination	Discharge, layoff, demotion, suspension, reinstatement, recall, involuntary retirement, or early retirement incentive	879	72.7	904	70.0

NOTE. Allegation categories are not mutually exclusive.

\* $P \leq .001$ .

Study 1—Table 2. Allegations and Merit Post ADA Amendments Act

Outcome	OR	95% CI	
		Lower	Upper
<b>Allegations</b>			
Hiring	1.01	0.71	1.42
Terms*	1.34	1.11	1.61
Relations†	1.48	1.23	1.78
Reasonable Accommodations	1.12	0.94	1.33
Termination	0.90	0.75	1.07
<b>Merit</b>			
Hiring	1.32	0.80	2.18
Terms‡	1.35	1.03	1.77
Relations	0.94	0.70	1.24
Reasonable Accommodations	1.28	0.99	1.66
Termination	1.06	0.87	1.30

Abbreviation: ADA, Americans with Disabilities Act; OR, odds ratio.

\*P < .01

†P < .001

‡P < .05.

Study 1—Table 3. Resources for Providers

Topic	Resources
Sample questions	<p>Are there any discrepancies among a patient’s current symptoms, function, and both typical and peak work demands?            Is a patient having difficulty meeting work demands?            How is the quality of a patient’s workplace relationships (coworkers and supervisors)? Has it changed?            Is there any support for a trial of a reasonable workplace accommodation?</p>
Workplace accommodations	<p>Problem-solving meeting with employer representatives and patient with cancer or cancer survivor to discuss, problem solve for potential alternatives, establish time frame for implementation, and jointly determine reasonable outcome expectations of such efforts (ie, improved work outcomes and quality of work life).            Telecommuting            Flexible work schedule            Reduced hours initially, with gradual increase over a reasonable, but well-specified, time, with recognition that the time period may be flexible            Job sharing: moving to part-time employment and working up to full time, or keeping it part time            Increase in frequency of breaks or rest periods            Changes in the physical environment at work—perhaps use an expert in office or other type of workplace ergonomics (eg, occupational or physical therapist) with the goals of reducing fatigue and/or cognitive distractions related to certain identified physical aspects of the work, and improving work outcomes (ie, speed, quantity, or quality of work).            Caution: It is important to point out that positive outcomes are not always achieved with the accommodation process for many reasons. Impact of disclosure to employers regarding cancer history should always to be carefully considered.</p>
Case example 1	<p>Description: 37-year-old woman diagnosed with stage II breast cancer. The patient was treated with chemotherapy and radiation and has since experienced prolonged fatigue, organizational problems, and difficulty with memory. She reported that, even though she had been a top sales performer for 15 years, it was difficult to remain working at this job creating new accounts because she became tired during the day and often forgot to follow up on certain tasks. She continued to miss work as well. Her salary, with commission, represented 77% of the family income. She also had three children all under the age of 12 years and needed to share the childcare responsibilities with her husband. Her employer’s expectations of her performance had returned to those he held before her cancer diagnosis and treatment, and he could not understand why her fatigue and memory problem persisted after treatment and no evidence of cancer. During this time, she was called weekly by the director of human resources, who informed her that there was no reason she should be experiencing fatigue, she should report to work immediately, and “the vacation was over.” After a year, the employer simply terminated her. She filed an ADA allegation related to terms of employment, arguing that the employer should have been more flexible given her seniority. There was no flexibility given her seniority or attempt at any type of workplace accommodations for the reported problems she experienced completing certain job tasks. She also submitted an allegation of harassment citing the repeated phone calls that she received by human resources.</p> <p>Suggestions: In this case, a simple set of questions early after primary treatment may have detected challenges in work. On recognition of these challenges, joint problem solving (employer, employee, provider) may have identified the need to recognize, acknowledge, and discuss with the employer potential workplace challenges due to fatigue and cognitive limitations that can have an end point. If this communication and problem solving had occurred, perhaps the employer would have been open to a more flexible stance, considering some accommodation, such as a change in hours or telecommuting to break up the week. This discussion could also have facilitated employer recognition that, although some patients exposed to certain treatments may experience prolonged fatigue and a change in speed of mental processing, these problems can attenuate over time. Therefore, the flexibility and accommodation may be only short term. The employer could have given the new plan a chance rather than immediately ignore the employee’s seniority and replace her. Given the employee’s performance in the past, and her seniority in the company, the employer may have been open to trying to accommodate and/or provide her with more time to recover sufficiently to meet work demands. Often the employee working on their own, or with a supervisor, can come up with suggestions that may help keep them at work. Discussion with a supervisor or human resources staff member can help with flexible possibilities, including potentially effective accommodations. Also, it was clear that the weekly phone calls from human resources could have been more supportive in terms of language used and tone. Often, returning to work or remaining at work with a chronic illness is a trial-and-error process, but it does require workplace support for its success.</p>
Case example 2	<p>Description: 48-year-old man with stage II glioma. The patient was treated with chemotherapy and radiation and has since reported mild depression, fatigue, and problems remembering things that needed to get done at work. He was an accountant for a midsized accounting firm. Months after primary treatment of his brain tumor, surveillance visits showed no evidence of the tumor, but he continued to experience problems at work, especially with scheduling and remembering to follow up on his offsite audits. For years he was a first-rate employee and had kept up with work without any problems before diagnosis and treatment. This change in productivity caused considerable friction between the director of corporate finance and the patient. After a year of episodic absences from work for doctor visits, his depression, fatigue, and some of forgetfulness began to subside, and much of his work productivity returned. Nevertheless, he was passed over for promotion to associate director that he was told several times in the past that he would transition into once the current associate director retired. He filed an ADA allegation stating that he was passed over for promotion (terms) because of his brain tumor. When the allegation was finally presented to the EEOC, it was determined to have merit; nevertheless, he left the company.</p> <p>Suggestions: In this case, if there had been some employer recognition that the employee’s symptoms could be related to diagnosis and/or treatment, and if some type of accommodation (eg, scheduling fewer on-site visits per day) were made until the employee’s symptoms became less severe, the work environment may have been perceived as more supportive and this employee may have remained at work. In these instances, it can be helpful for the patient to break down work tasks with which symptoms interfere and generate options (accommodations) that may help them</p>

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improve their productivity. For example, if this patient is experiencing difficulty because of forgetfulness, he can take advantage of his smartphone to provide simple reminders. If he is just too tired to visit five clients per day as before, he can choose to reduce his schedule temporarily and gradually increase the number of client visits per day. Potential solutions can be simple when flexible. The following steps may be helpful: break large challenges down and focus on one problem at a time, identify what is getting in the way of completing the work task or tasks, generate potential solutions to solve the problem, implement a solution that seems the simplest, and evaluate whether the solution was helpful. This process continues until some solution works. If the patient cannot do this on his own, perhaps an oncology nurse coordinator can work with the patient. When it seems that a problem is just too complex and time consuming, consider referral to vocational counseling services (either private or state-supported).  
Note: Health care provider involvement requires explicit consent by the patient/employee to disclose a cancer diagnosis to an employer.

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To learn more...

Review of worker, workplace, and policy factors related to work outcomes in cancer survivors (40)  
Review of literature on accommodations from employee, workplace, and organization perspectives (89)  
Questions & Answers about Cancer in the Workplace and the Americans with Disabilities Act (ADA) (138)  
Employment rights (107)  
Job Accommodation Network (88)  
Americans With Disabilities Act: Information for People Facing Cancer (5)  
Enforcement Guidance: Reasonable Accommodation and Undue Hardship Under the Americans with Disabilities Act (137)  
Cancer and Careers (1)

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Study 2—Table 1. Demographic and Employer Characteristics

	No Comorbidities (n = 958)	1+ Comorbidity (n = 333)
	n (%)	n (%)
Female	628 (66)	208 (63)
Employer Size		
15-100	291 (30)	93 (28)
101-200	87 (9)	35 (11)
201-500	152 (16)	36 (11)
501+	428 (45)	169 (51)
Region		
Southeast	235 (25)	82 (25)
Midwest	219 (23)	62 (19)
Southwest	172 (18)	56 (17)
Mid Atlantic	83 (9)	43 (13)
Other	89 (9)	33 (10)
Pacific	90 (9)	29 (9)
Northeast	70 (7)	28 (8)
	M(SD)	M(SD)
Age	49.65 (9.22)	49.31 (9.29)

*Note.* No significant differences.



Study 2—Table 2. Comorbid Conditions Across Cancer Survivor Claimants

Condition	n	%
<b>Behavioral</b>		
Depression	47	14.1
Anxiety disorder	11	3.3
Other psychiatric disorders	7	2.1
Manic depression (bipolar disorder)	6	1.8
Learning disability	2	0.6
Alcoholism	1	0.3
<b>Medical</b>		
Diabetes	29	8.7
Orthopedic/structural back	28	8.4
Heart/cardiovascular	25	7.5
Neurological—Other (Parkinson's Disease, Hydrocephalus, narcolepsy, sleep apnea, muscular dystrophy)	19	5.7
Non-paralytic orthopedic	17	5.1
Kidney	12	3.6
Gastrointestinal	11	3.3
Pulmonary/Respiratory—Other (emphysema, acute bronchitis)	10	3.0
HIV/AIDS	9	2.7
Blood—Other (anemia, sickle cell, and Lupus)	6	1.8
Traumatic brain/head injury	5	1.5
Asthma	5	1.5
Paralysis	4	1.2
Multiple sclerosis	2	0.6
Epilepsy	2	0.6
Dwarfism	1	0.3
<b>Sensory</b>		
Hearing	6	1.8
Vision	5	1.5
Speech	5	1.5
<b>Nonspecific</b>		
Disabled, undefined	166	49.8
Missing digits/limbs	2	0.6
Chemical sensitivity	2	0.6
Disfigurement	1	0.3

Study 2—Table 3. Workplace Discrimination Claims under the Revised Americans with Disabilities Act

Allegations		No Comorbidities n (%)	1+ Comorbidity n (%)
Hiring	Hiring, prohibited medical inquiry, training, job classification, qualification standards, referral, testing, apprenticeship, advertising	53 (6)	20 (6)
Reasonable Accommodations	Reasonable Accommodations	287 (30)	102 (31)
Terms of Employment	Terms and conditions, promotion, wages, benefits—insurance, union representation, benefits—retirement/pension, waivers, exclusion, seniority, severance pay denied, maternity, tenure, posting notices, segregated facilities, and segregated local unions	246 (26)	107 (32)
Relations	Harassment, discipline, constructive discharge, assignment, intimidation, references unfavorable, or breach of confidentiality	263 (28)	100 (30)
Termination	Discharge, layoff, demotion, suspension, reinstatement, recall, involuntary retirement, or early retirement incentive	673 (70)	231 (69)
Merit	Determined to have merit by review from regulating bodies (i.e., the Equal Employment Opportunity Commission or federal courts)	283 (30)	96 (29)

*Note.* Allegations of discrimination are not mutually exclusive.

Study 2—Table 4. Results of Primary Analyses: Factors Related to the Presence of Comorbidities

	OR	95% CI
Hiring Claims	1.09	0.64-1.85
Terms of Employment Claims	1.37*	1.04-1.80
Relations Claims	1.13	0.86-1.49
Reasonable Accommodations Claims	1.03	0.79-1.35
Termination Claims	0.96	0.73-1.25
Merit of Claims	0.97	0.73-1.27

*Note.* Each line represents the results of a separate logistic regression; OR = Odds Ratio; CI = Confidence Interval; Merit = Discrimination claims found in favor of claimant.

\* $p \leq 0.05$

Study 2—Table 5. Results of Post-Hoc Merit Analysis: Terms of Employment Factors Related to Merit

	OR	95% CI
Terms of Employment Claims	1.44*	1.06-1.96
Comorbid Condition	0.93	0.66-1.31
Terms of Employment Claims x Comorbid Condition	1.04	0.58-1.86

*Note.* OR = Odds Ratio; CI = Confidence Interval; Merit = Discrimination claims found in favor of claimant

\* $p \leq 0.05$

Study 3—Table 1. Sample Characteristics

Demographic	n (%)	Clinical	n (%)
Age		Stage	
35-44	3 (27.3)	Stage I	5 (45.5)
45-54	4 (36.4)	Stage II	2 (18.2)
55-64	3 (27.3)	Stage III	3 (27.3)
65-74	1 (9.1)	Missing	1 (9.1)
Highest Education		Surgery	
High school	1 (9.1)	Lumpectomy	5 (45.5)
Associate's degree	1 (9.1)	Mastectomy	6 (54.5)
Bachelor's degree	3 (27.3)	Radiation	
Graduate degree	6 (54.5)	Yes	9 (81.8)
Marital Status <sup>1</sup>		No	2 (18.2)
Married	10 (90.9)	Chemotherapy	
Divorced	1 (9.1)	Yes	6 (54.5)
Race		No	5 (45.5)
Caucasian	8 (72.7)	Hormonal Therapy	
Black or African American	1 (9.1)	Yes	8 (72.7)
Asian	1 (9.1)	No	3 (27.3)
Decline to respond	1 (9.1)	Months Post Primary Treatment	
Identify as Hispanic or Latino		Median (SE)	2.43 (0.5)
No	9 (81.8)	Menopausal Status	
Decline to respond	2 (18.2)	Pre-menopausal prior to cancer, post-menopausal after treatment	1 (9.1)
Employment Status		Pre-menopausal prior to treatment, pre-menopausal after treatment	2 (18.2)
Work full-time	6 (54.5)	Post-menopausal before diagnosis or treatment	6 (54.5)
Work part-time	1 (9.1)	Decline to respond	2 (18.2)
Unemployed (by choice)	2 (18.2)		
Unemployed (not by choice)	1 (9.1)		
Decline to respond	1 (9.1)		
Job type			
Professional	4 (36.4)		
Management	2 (18.2)		
Other	1 (9.1)		
NA-Unemployed (by choice)	2 (18.2)		
NA-Unemployed (not by choice)	1 (9.1)		
Decline to respond	1 (9.1)		
Household Income			
\$80,000 - \$99,000	2 (18.2)		
\$100,000 or more	6 (54.5)		
Decline to respond	3 (27.3)		

Study 3—Table 2. Perceptions of App Components and Related Procedures (N = 11)

	Yes n (%)
<b>Survey</b>	
Covers major problems experiences by BCS	10 (90.9)
Cover the problems that you have experienced	7 (63.6) <sup>1</sup>
<b>Amount of Time</b>	
Took just about the right amount of time to complete	10 (90.9)
Took too long to complete.	1 (9.1)
Did not take enough time to complete.	0 (0.0)
I could see the questions clearly on the tablet.	11 (100.0)
There were too many questions on each page	1 (9.1)
The tablet was a simple way to complete the CSPro.	11 (100.0)
I felt overwhelmed taking this survey on the tablet.	2 (18.2)
<b>Graphic Output</b>	
Provided me with a clear idea of areas that I need to follow up on in the next three months.	10 (91)
Displayed all 18 problem areas in an understandable manner.	10 (91)
Used colors that helped me to clearly identify problem areas.	10 (91)
Provided a communication tool for discussing problem areas with my nurse.	11 (100)
Could stand on its own with little explanation.	9 (82)
Could stand on its' own after a one-time explanation of the results.	10 (91)
Seemed like a waste of time - I knew this already.	0 (0)
The explanation of the CSPro output helped with my understanding of what my challenges are now as a cancer survivor.	9 (82)
The explanation of the recommendations and resources helped me understand how to address my challenges as a cancer survivor.	11 (100)
<b>Online Resources</b>	
Overall, the online resources provided seem like they would help address the problem areas identified in my CSPro output.	8 (89) <sup>2</sup>
Overall, the community resources provided seem like they would help address the problem areas identified in my CSPro output.	8 (89) <sup>2</sup>
Overall, the recommended self-management approaches (e.g. healthy eating, exercise) seem like they would help address the problem areas identified in my CSPro output.	10 (91)
Overall, the recommended referrals seem like they would help address the problem areas identified in my CSPro output.	9 (90) <sup>3</sup>
<b>Brief Training in Problem Solving</b>	
The nurse's problem solving explanation was clear.	11 (100)
I am confident that the problem solving approach can help me generate new ideas on how best follow through efforts to improve problems that were identified by the CSPro.	10 (90.9)
I am confident that I will use the problem solving strategies in the future.	9 (81.8)
Practicing the problem solving strategies helped to make the approach clearer.	9 (100) <sup>2</sup>
The problem solving wheel will be a good reminder of what options I might take to solve a problem.	10 (90.9)

*Note.* All Likert scales ranged from 0 – 10. For ease of interpretation, Likert scale responses were transformed in to dichotomous variables where 0-5 = No and 6-10 = Yes.

<sup>1</sup>Three cases replied NA, one case declined to respond.

<sup>2</sup>n = 9 due to two cases with missing data.

<sup>3</sup>n = 10 due to one case with missing data.

Study 3—Table 3. Changes to CSPro and Delivery

Source	Themes	Changes
BCS	Overall Use -Do not access resources after appointment	<b>Take Home Guide and In-Person Planning</b> Include behavioral plan in the take-home guide outlining plan for flash drive and hard copy profile (i.e., where they will keep it, what device they will use it on, when will they use it, what will they do if they have questions) and including a confidence rating of following through with this plan. Template is completed at the end of clinic appointment. <b>Add Weekly Follow-Up Email:</b> Send a weekly follow-up email for the duration of the study to maintain engagement and prompt online resource use. Weekly check in to include a brief (5 minutes) survey on online resource use.
	Graphic Display -More Guidance Needed -Difficult to Interpret	<b>Take Home Guide and In-Person Training</b> Provide more explicit guidance for home use during the appointment. Also, include detailed, easy-to-follow instructions in take home guide on how to access each of the CSPro components, as well as what the purpose and utility of the profile.
	Flash Drive and Resources -More Guidance Needed	<b>Take Home Guide and Expand In- Person Training</b> Provide more explicit review on how to access and navigate the online resources during the appointment. Also, include detailed, easy-to-follow instructions within the take-home guide.
	Resources -Information Overload	<b>Reformat and Reduce Resources</b> Eliminate overlapping resources to reduce overall number and specify type of resource (i.e., “helpful tool” or “description”)
	Resources -Potential Link Expirations/ Changes	<b>Implement a Regular Link Check Procedure</b> Check links every month to ensure they are functioning. If not, revise them accordingly. If location of website has changed, simply update link. If website has been deleted locate similar website and change resource to that link.
	Non-Flash Drive Format Preferred -Hard Copy -Tablet-Based	<b>Unable to Address-Information Technology Restrictions</b> The researchers selected the flash drive medium over an electronic communication-based medium (e.g., email or online portal) because of restricted access to secure health record-based messaging and HIPAA concerns surrounding alternative methods of electronic communication. Providing multiple methods for accessing the recommended resources should be considered in future applications.
Nurse Navigators	Minimize Time Required by Nurse Navigator	<b>Adjust Timing of Survey Delivery</b> Complete the CSPro survey prior to the nurse navigator appointment
	Need a list of the CSPro-Breast questions used to calculate the score of each problem area. This would allow for elaboration on the specific items of problem areas to increase the clinical utility of the app within the survivorship visit.	<b>Provide Items used in Survey to Nurses</b> Give nurses a hard copy of the questions by problem area as part of the CSPro app intervention. Display the questions for the red and yellow highlighted scales within the APP output.

*Note. The take-home guide is available upon request by emailing [jcancersurvivorship@gmail.com](mailto:jcancersurvivorship@gmail.com).*

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