Original Article

Employment Challenges for Cancer Survivors

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There is a considerable body of evidence about the adverse effects of cancer and cancer treatments on employment, work ability, work performance, and work satisfaction among cancer survivors. There is also a growing consensus that cancer survivorship research needs to address the large variety of short-term and long-term work-related problems and that programs to support return to work and employment should be developed and integrated into the follow-up survivorship care of cancer patients. Cancer survivorship and employment can be considered from the perspective of the cancer survivor, the caregiver and the family, the employer and coworkers, the health care providers, and the community or society—elements that comprise many similarities but also differences between Europe and the Unites States and that may affect employment and return to work among cancer survivors in different ways. Previous research has specifically addressed the likelihood and timeliness of work return, including factors that promote and hinder return to work and work performance, and intervention studies and programs that focus on psychological, physical, pharmacologic, or multidisciplinary approaches to work. The area of work disability has emerged as an international field with research from areas throughout the globe. In this article, the authors provide an overview of the current state of scientific research in these areas and further provide a cancer survivorship and work model that integrates significant individual cancer-related, treatment-related, and work-related factors and outcomes. The report concludes with a discussion of European and American contributions and possible future directions for the enhancement of current efforts. ***Cancer*** **2013;119(11 suppl):2151-59.** *© 2013 American Cancer Society.*

KEYWORDS: cancer; employment; work; disability; survivorship.

INTRODUCTION

More individuals are surviving cancer than ever before, particularly in the high-income countries, because of early diagnosis and improvements in multimodal cancer treatments. Breast, prostate, lung, and colorectal cancers are the most common forms of cancer among women and men worldwide. In Europe, the 5-year prevalence includes a total of 8.5 million individuals.[1] In the United States, the number of cancer survivors increased in the last 30 years from 3 million in 1971 to 11.7 million in 2007, an increase from 1.5% to 4% of the US population.[2] Annual cancer incidence data from Europe and the United States indicate that an estimated 43% to 44% of all cancer patients are diagnosed between ages 15 and 64 years, and between 56% and 57% are diagnosed between ages 15 and 69 years,[1] an age when work life plays an important role.

Given the reality that life expectancy has continually increased in European countries and in the United States—countries with a high Human Development Index[3]—in addition to the traditional age range of the labor force, more and more older individuals are expected to remain in the workforce. Thus, surviving cancer leads to new challenges with regard to employment and work that can play a significant role in the global economy given the growing needs of cancer survivors in both the short-term impact and the long-term impact of cancer and treatment. Cancer survivorship and employment can be considered from different perspectives: 1) the cancer survivor (eg health, quality of life, work ability, job satisfaction, return to work, employment discrimination), 2) the caregiver and the family (eg the burden of care, partnership

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European-American Dialogues on Cancer Survivorship: Current Perspectives and Emerging Issues

This supplement was guest edited by Vittorio Mattioli, MD (NCRC, Bari, Italy) and Kevin Stein, PhD (American Cancer Society, Atlanta, Georgia) and was produced with the authoritative contribution of 58 authors from the European Union and the United States. The primary aims are to highlight the potential differences between European and American approaches to cancer survivors' issues, increase coordination among oncologists and other primary care providers, and aid the development of a shared care model that can improve the quality of cancer care.

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issues, financial problems, risk for poverty), 3) the employer and coworkers (eg working conditions, work load, working arrangements), 4) the health care provider (eg supportive care and rehabilitation needs, effective support programs and interventions), and 5) the community or society (eg economic and policy changes).

Between Europe and the United States, there are several differences in terms of health care provision and social security that affect employment and return-to-work in cancer survivors. With regard to legislation on sick leave and sickness benefits, all European countries provide several types of social insurance systems for employees and, in some countries, self-employed individuals as well.[4] However, there are major differences among countries in terms of solutions for employees with chronic health conditions and the unemployed. The Nordic European countries provide a very comprehensive social system for employees with chronic illness, whereas the majority of Continental/Mediterranean countries ensure no specific protection for the unemployed.[4] In most European countries, the amount of benefit is related to the earnings or income of the employee; in some countries, such as Belgium and the United Kingdom, a lump sum or a flat rate benefit is paid. Also, the duration of sickness benefit differs across European countries from a minimum of 6 months to a maximum of unlimited duration.[4] Alternative measures and policies to sick pay allowance can be divided into 3 categories: 1) measures aimed at adapting the workplace and work activity to workers' reduced capacity, 2) measures aimed at fostering life-long learning, and 3) measures aimed at removing individuals from the workplace whose reduced work capacity does not allow them to perform the assigned tasks (or any other task).[4]

In the United States, the health and social network for those who are work-disabled consists of numerous programs, including Social Security (eg, retirement, survivors, and disability insurance), Medicare, unemployment insurance, and supplemental security income. Concerning general health insurance, the employee is often insured by the employer. However; insurance for both health care and indemnity (lost time or 100% work disabled) is also provided through federal programs to which the employee contributes during their working years.

Related to the matter of paid sick leave, there is no national policy related to standard coverage for employees. Clearly this is not the case in countries within the European Union. This policy variation between the United States and the European Union certainly can influence decisions regarding work status at the time of treatment for cancer; however, the US federal government, by implementing the Family and Medical Leave Ac, at least provides 12 weeks of unpaid, job-protected leave.[5] We are unaware of comparisons to date across countries of the effects of such discrepancies on work disability in cancer survivors. However, in relation to this matter, there is anecdotal evidence that, even with short-term disability coverage, cancer patients are deciding not to initiate such coverage and report wanting to work during treatment and/or to use sick leave benefits to cover time lost related to treatment for cancer and its long-term effects.

Employment and Return to Work

Over the past 2 decades, a considerable amount of research has demonstrated the significant physical, emotional, and social impact of cancer and its treatment on patients and their families. However, as the increase in cancer incidence and the improvement in survival rates have led to a growing number of cancer survivors, the importance of work ability, (re-)employment and social reintegration have gradually emerged as critical topics within psycho-oncologic and cancer survivorship research.

Because returning to work has great importance for patients and society, the majority of studies that have specifically addressed cancer and work outcomes have been focusing on the likelihood and timeliness of work return. The work participation of cancer survivors typically has been assessed by measurements like employment status (yes/no)[6] or the length of sick leave, as reflected by the number of days off work after diagnosis.[7] Several review articles from both the United States and the European Union have summarized return-to-work studies and have reported average return-to-work rates of approximately 64%, with a wide range between 24% and 94%.[8-13] However, a meta-analysis by de Boer et al[10] indicated that the unemployment risk was 1.48 times higher (95% confidence interval, 1.15-1.98) in the United States than in European countries. Overall, studies have indicated a steady increase in return to work with increasing time intervals after a cancer diagnosis (Table 1).[13] These results were based mainly on populations with early stage breast cancer or mixed populations with breast cancer, gynecologic cancers, and a variety of other tumor entities, such as gastrointestinal, hematologic, and urologic, cancers.[13-24] Roelen et al[25] demonstrated that, 2 years after a cancer diagnosis, the highest percentage of patients who had fully returned to work were those who had female genital cancer, male genital cancer, skin cancer, and breast cancer. The lowest percentage of patients who returned to work were those who had lung cancer and gastrointestinal cancers.[25] Moreover, advanced cancer stages and palliative treatment

TABLE 1. Percentages of Patients Who Returned to Work After Cancer Diagnosis

Time After Diagnosis	Percentage of Patients (Range)
RTW 6 mo after diagnosis	40 (24-72)
RTW 12 mo after diagnosis	62 (50-81)
RTW 18 mo after diagnosis	73 (64-82)
RTW 24 mo after diagnosis	89 (84-94)
RTW 5 y after diagnosis	67 (1 study)

Abbreviations: RTW, returned to work.
[a]Based on data from: Mehnert A. Employment and work-related issues in cancer survivors. *Crit Rev Oncol Hematol*. 2011;77:109-130.[13]

intention were associated with lower return-to-work rates.[26]

Research has indicated that the risk of unemployment was associated with extensive surgery and advanced tumor stage.[15,22,26-29] Also, a range of tumor entities has been associated with a greater risk of unemployment and job loss, including liver, lung, and brain cancers; hematologic malignancies; gastrointestinal and pancreatic cancers; as well as head and neck and gynecologic cancers.[10,27,28,30-32]

Perceived employer accommodation for cancer-related and treatment-related symptoms and side effects, long-term or late effects, and follow-up medical visits has been identified as a strong predictor of return to work.[8,22,26] In cancer survivors, a return-to-work meeting with the employer as well as advice from a physician about work, flexible working conditions, counseling, miscellaneous training services, job replacement services, job search assistance, and maintenance services were factors significantly associated with a greater likelihood of being employed among cancer survivors in both the United Kingdom and the United States.[17,26,33,34] Studies from European countries, such as Finland, Germany, and the Netherlands, identified younger age, higher levels of education, absence of surgery, fewer physical symptoms, shorter duration of sick leave, male gender, and Caucasian ethnicity as variables that were predictive of or associated with return to work.[13,17,19,21,31,35-37]

In addition to return-to-work and sick leave duration outcomes, the performance of the cancer survivor once back at work has not been regularly investigated. Breast cancer survivors[38] and brain tumor survivors[39] self-reported significantly lower work productivity than their peers who never had cancer, whereas breast cancer survivors had a mean reduction in productivity of 2.5 hours of work over 2 weeks.[40] All of those studies were conducted in the United States. Studies focusing on work ability indicate that higher levels of fatigue or cognitive limitations are associated with decreased work ability.[9,16,27,41-46] These findings have been reported in research both on American and European cancer survivors. In a recent Norwegian study, 31% of the employed cancer survivors (80% were engaged in nonmanual work) reported a reduction in physical work ability because of cancer, whereas 23% reported a reduction in mental work ability.[47]

Some qualitative studies conducted in the United Kingdom, the United States, and Canada using interviews and focus groups have examined the impact of cancer on the survivor's subjective experience of work life. Patients who were 1 to 10 years postdiagnosis reported that they had difficulties coping and concentrating, and they were worried about their reduced work capability.[46] Returning to work after treatment for cancer can alter the patient's job position. Breast cancer survivors reported experiencing unwanted changes in their jobs and job responsibilities, in addition to changes in their relationships with coworkers and employers[48]; these women also reported a change in their feelings about the importance of work. This latter study was reported from Canada and in a province with strong organized labor.

Other qualitative studies on subjective experiences of cancer patients also have indicated that their cancer had influenced their priority of work relative to other aspects of their lives[49] or had deteriorated their job satisfaction and career prospects.[21] Currently, there are few quantitative studies from either the United States or the European Union that provide information about how cancer survivors experience the quality of their working life in terms of job-related well being, work pleasure, and the extent to which work experiences are rewarding, fulfilling, and devoid of stress and other negative personal consequences.[47]

Conceptual Framework

Developing a better understanding of cancer and treatment-induced, work-related problems and the specific targets for work-related interventions and rehabilitation programs will facilitate cancer survivorship research and practice in the area of work and cancer. Figure 1 is a cancer survivorship and work model adapted from Feuerstein et al[12] and Mehnert[13] that illustrates the range of individual and interpersonal factors and the short-term, long-term, and late effects of cancer treatments as well as the work environment and overall legal, organizational, and financial policies and procedures that may affect employment and return to work. Specific interventions and rehabilitation programs should to be further developed, evaluated, and implemented that address a variety of individual and

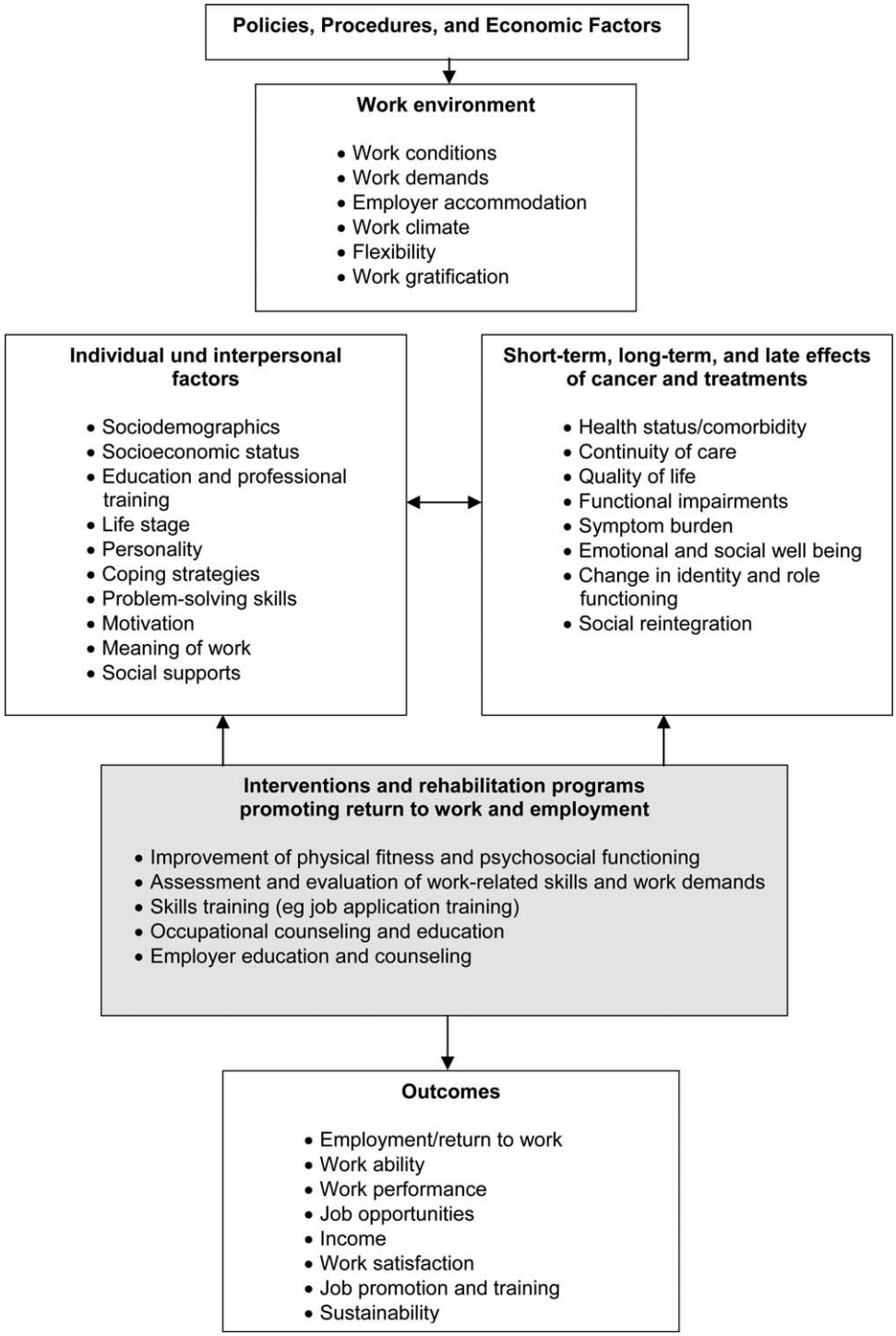

Figure 1. The cancer survivorship and work model is shown.

treatment-related factors and that are tailored to the individual needs of a patient. On the basis of existing research, such programs should focus on the evaluation and targeted intervention related to physical and psychosocial function, symptom burden, work environment, and organization-related and policy-related factors. This approach has the potential to address work-related outcomes, such as employment, work ability, or work performance.

Rather than pointing out differences in the 2 conceptualizations, we thought that it would be more useful to integrate the 2 frameworks. Merging concepts from both of these models, in which both frameworks are based on evidence from studies conducted on both continents, made sense given a focus on parsimony and applicability. The integrated model emphasizes 4 major areas, including individual and interpersonal factors (eg sociodemographics, education and professional training, meaning of work); short-term, long-term, and late effects of cancer and cancer treatments (eg functional impairments, symptom burden); the work environment (eg working conditions); and outcomes, such as employment or work performance (Fig. 1). An intervention element was included to highlight various approaches that can improve work outcomes. The focus on several work outcomes is consistent with potential outcomes in the work disability area.[50,51] Other work-related outcomes that have been considered in the cancer survivor literature include changes in work ability, career choices, work productivity, and work retention or sustainability. Figure 1 provides a more complete list of possible work outcomes.

Intervention Studies and Programs

Given the importance of employment for cancer survivorship and quality of life, it is necessary to provide employed cancer survivors with programs to support the return-to-work process, work retention, and other outcomes, as listed in Figure 1. In the past 2 decades, interventions have focused on either psychological, physical, pharmacologic, or multidisciplinary approaches to work or on modifying various problem areas in cancer survivorship that can influence work outcomes.[50,51] In the United States and in European regions, programs to enhance labor participation of cancer survivors have been reported. These initiatives typically focus on providing strategies that often are focused on the cancer survivor rather than the broader workplace, economic, or related policy areas. Future interventions should more centrally include the perspective of coworkers and employers with regard to the structuring of work organization, the deployment of workers, work-related training, skills training opportunities, and professional development to learn adaptive ways of dealing with new demands and unfamiliar work situations in working with individuals who have cancer and other chronic health conditions.

In a recent *Cochrane Review*, the effectiveness of interventions that constituted randomized controlled trials to improve work outcomes was reported.[6] Until now, the research on evidence-based interventions to achieve changes in various work outcomes has been very modest. This work was conducted with cancer survivors from both the United States and Europe. There were no interventions identified in which the primary focus was to improve return-to-work outcomes or, for that matter, any work-related outcome. Modest evidence indicated that multidisciplinary interventions involving physical, psychological, and vocational components led to higher return-to-work rates than care as usual. Two of the effective multidisciplinary interventions were conducted more than 30 years ago by an oncology nurse in the hospital setting.[52,53] However, to our knowledge, there are no data on the cost of such efforts.

In the early United Kingdom study by Maguire et al,[52] patients with breast cancer were advised by an oncology nurse on exercise, were encouraged to return to work and become socially active, and were counseled on feelings. The nurse began the intervention in the hospital early after surgery and followed the patient every 2 months to monitor their progress until the patient "adapted" psychologically and socially to the new situation. Twelve to 18 months after surgery, those who were helped by the nurse had greater social recovery, return to work, and adaptation to breast loss than those without the nurse's support.[52] Berglund et al[53] developed an intervention in Sweden for patients with breast cancer in which the patients received information and performed physical training supplemented by coping skills training provided by an oncology nurse who specialized in psychosocial matters. In a randomized trial, patients with breast cancer in that program had improved return-to-work outcomes, but no statistically significant differences were observed when those patients were compared with controls who received either a single information session or no intervention.

Various occupational rehabilitation interventions have been developed in Europe. A Dutch program,[54] in which the medical specialist provided a 10-step plan with advice to the patient on returning to work, demonstrated that patients adhered to 7 of the 10 suggestions in the leaflet, and half of the occupational physicians perceived that the guidance they provided was helpful.[54] In a more recent intervention, a psycho-oncology nurse supported cancer patients with returning to work in a work-directed intervention consisting of 4 meetings with a nurse at the treating hospital to start early vocational rehabilitation and supply work-related and legal information; 1 meeting with the participant, occupational physician, and supervisor at work (line manager) and letters from the treating physician to the occupational physician to enhance

communication.[55] A randomized controlled trial evaluating the effects of this intervention is currently underway. In the United Kingdom, a self-management tool for employees affected by cancer (entitled "Work It Out") was recently developed. This empowerment-based approach enables individuals affected by cancer to find solutions in making a timely return to work or to maintain employment during diagnosis and treatment. The project used intervention mapping, which is a process for developing theory-based and evidence-based health education programs, and a Delphi consensus method[56] to develop and test the tool. A feasibility study demonstrated that most participants considered the information and advice on the impact of treatment on work ability most valuable. Most participants felt that specialist cancer nurses and consultants were best placed to deliver return-to-work interventions.[57]

The Spanish Association Against Cancer, in coordination with the Employment Service in Andalusia, has been working since 2005 on a job placement program to promote social-labor integration of cancer patients. The program emphasizes modifying factors in the job placement process, especially those related to cancer. For the early detection of those factors, an adapted Job Placement Psychological Factors Questionnaire is employed. Analysis of those elements, along with a customized employability diagnosis, provides the adoption of specific strategies for each cancer patient.[58] The program's job placement rate is 62.5%. This is probably a relatively good outcome, because the program is focused on individuals who have problems returning to work and need help with their labor integration. In an average population of cancer patients, the return to work is 62% after 12 months.[13]

Vocational rehabilitation services are available in both the United States and the United Kingdom for patients with cancer and are currently being evaluated. In Scotland, patients receiving employment support are allocated a case manager who conducts a telephone assessment of supportive care needs to facilitate remaining in or returning to work. On the basis of this initial assessment of each individual's personal goals and health status, the case manager directs participants to appropriate support services, including physiotherapy, occupational therapy, occupational health specialists, counselors/psychological therapy, and complementary therapy. Thus, each individual may receive a different intervention or a combination of interventions. A randomized pilot study has begun to evaluate the effects of this intervention.[59]

Young adult cancer survivors had lower levels of occupational development and were less ready to pursue employment compared with their noncancer survivor counterparts. In the United States, vocational services were offered by vocational counselors to young cancer survivors, although very few were involved in a state-federal rehabilitation program.[60] Despite this, the provision of certain vocational rehabilitation services was related to increased employment in these young adult survivors. Those who received job search assistance and on-the-job support were 4 times more likely to be employed after receiving such services.[60]

On the basis of social laws in Germany, cancer patients have a legal right to participate in a 3-week inpatient cancer rehabilitation program at specialized institutions.[61] Access to rehabilitation programs is usually facilitated by hospital physicians and social workers immediately after patients complete their primary treatment or at a later stage during the course of cancer. Rehabilitation costs are covered mainly by pension and health insurance. The cancer rehabilitation program has a multidimensional, therapeutic approach that includes patient education, exercise, and physical therapy to regain physical fitness and vitality along with relaxation training and psychosocial as well as occupational counseling to enhance coping skills and facilitate return to work at the earliest possible time. Specific programs for gradual reintegration into the working life are provided.

Research in the United Kingdom indicates that line managers and employers also need support to help their employees affected by cancer. For example, 1 study reported that 73% of employers in the United Kingdom had no formal policy for managing employees diagnosed with cancer, and only approximately 33% of organizations ensured that relevant staff had a good understanding of cancer and the impact of treatment on an individual's working role. The effect of this is that insufficient support and information are made available by employers to employees with cancer.[62] Furthermore, line managers treated referral to occupational health physicians differently for employees who had cancer compared with employees who had other diagnoses, with 45% of respondents indicating that referral may take place too late to be effective in securing a return to work.[63]

To overcome these barriers, the Danish Cancer Society is supporting employers by developing an employer's guide containing information, legislation, and practical advice about how to support employees affected by cancer. The guide is currently being adapted for other European countries. A similar guide has been developed by Macmillan Cancer Support in the United Kingdom,[64] but neither guide has been evaluated. A measure that

assesses a supervisor's level of support, referred to as the Supervisors to Support Return to Work measure, recently has been developed in the United Kingdom. This is a potentially valuable tool in research and in organizational settings, both during long-term sick leave and after employees have returned to work.[65]

European and American Contributions and Perspectives on Work and Cancer: Future Directions

Perhaps because of the global economy in the 21st century and the ease of communication among investigators in diverse countries with differing languages, health care systems, and social safety nets, there are many similar constructs and approaches to cancer survivorship and work. There also are conceptual frameworks that possess many of the same empirically supported and hypothetical associations.[12,13,66-68] Furthermore, in 2006, a group of researchers and clinicians interested in the impact of cancer on work and employment met in London and then again a year later in Spain at the International Psychosocial Oncology Society meetings to discuss this field, its current status, and future directions of this area of research. Many themes discussed in these initial meetings have been reflected in the subsequent research of the individuals who were in attendance. Beyond cancer, there has also been an increasing international focus on the field of work disability in general as well as how it applies to many types of chronic illnesses.[69] With regard to cancer survivorship research, previous studies have mainly focused on breast and gynecologic cancers, including mainly women. Future research should more strongly focus on patients with other cancer entities, such as gastrointestinal cancers or blood cancers, and on different age populations, such as childhood or adolescent cancer survivors.

Clearly, there are differences between the broad geographic areas of the United States and Europe in terms of the European research emphasis on many elements of the workplace rather than the worker.[70,71] This distinction has a long history in the area of work disability in general; however, investigators in the United States could learn from their European colleagues in terms of studying and addressing various aspects of the work environment and organization of work in those with various health problems. Another difference noted in the research between the 2 different entities is the use of work ability as an outcome measure in much of the European research and as more of a focus on measures of productivity in the United States. Although, at this point, both involve the perception of the affected worker and are not independent measures of perceived ability or productivity, the difference is interesting to point out. Perhaps the focus on performance at work is more consistent with the US culture, which focuses on output or productivity to a greater degree than quality of work life. Finally, the lack of research on violations of legal protections for cancer survivors in the workplace in European Union countries versus the United States may reflect a certain level of friction that rises to the level of legal remedy for perceived problems in the workplace in the United States, whereas these problems may be addressed in the routine management of work and health in the European Union.[72] This differential, although speculative, also may reflect a cultural difference in terms of the relative value of the quality of work life.

There are many similarities in terms of the factors associated with work problems across many countries, and these factors are robust despite differences in social systems, health care systems, language, and culture. Research on work disability and a variety of health problems has reported similar challenges and has identified many of the same factors related to work disability among many chronic health problems.[51] For example, problems in the area of work and cancer survivors share many concerns with research on work and disorders, and those studying cancer and work can learn from the decades of research in that area.[73] Cost-effective primary, secondary, and tertiary prevention efforts that address the many problems that serve as barriers to returning to work or work sustainability need to be pursued with vigor. Although we must learn more about the etiology and the impact of work disability among cancer survivors to titrate our interventions, now is the time to design and systematically evaluate various approaches based on our current understanding of cancer survivorship and work and the broad research base on work disability from other chronic illnesses.

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