

Michael Feuerstein

**WORK AND
CANCER
SURVIVORS**

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Work and Cancer Survivors

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Chapter 12 Individuals with Cancer in the Workforce and Their Federal Rights

Peter Blanck, William N. Myhill, Janikke Solstad Vedeler, Joanna Morales,
and Paula Pearlman

Introduction

It is not uncommon for employers and co-workers to have misperceptions about an individual's ability to work during and after undergoing treatment for cancer [1]. One in four individuals with cancer faces some form of discrimination in the workplace [2, 3]. In the United States, federal laws provide job protection from discrimination to individuals with cancer, such as the Americans with Disabilities Act of 1990 (ADA) and the Family and Medical Leave Act (FMLA). This chapter investigates the effectiveness of these laws in protecting the jobs, quality of life, and livelihoods of individuals in the workforce who are diagnosed with cancer.

In Part I, we review the work and home life of individuals with cancer, especially during illness, diagnosis, and on through the often extensive periods of treatment and recovery, collectively addressed as cancer survivorship in the present volume. These observations of work and home life that describe many situations among cancer survivors need to be considered as the backdrop for existing laws that are presumed to apply to many of the challenges that cancer survivors face. In Part II, we explain the applicable federal laws for the employee diagnosed with cancer. Then in Part III, through the experience of Patricia Garrett, a woman who survived breast cancer at the expense of her career, we present the challenges of invoking ADA and FMLA protections on the job and in the courtroom. Part IV reviews the larger picture of federal protections in light of the *Garrett* decision and emerging shifts in the law. Part V provides resources and best practices for employers and employees diagnosed with cancer, and future directions for the law. We close this chapter with recommendations for respecting and asserting ADA and FMLA protections.

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M. Feuerstein, *Work and Cancer Survivors*, DOI 10.1007/978-0-387-72041-8_12,
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Key Issues Facing Persons with Cancer

The journey of an individual with cancer may be characterized as a roller coaster ride [4], impacting family and work relationships, and affecting a person's physical and psychological condition. A cancer diagnosis may also affect how others perceive the person, thereby impacting interpersonal arenas, like the family and the workplace. How these relationships play out in turn influences the social well-being of individuals with implications for quality of life [5].

Personal and Family Experiences

Cancer diagnosis impacts the whole family and in multiple ways [6]. Persons with cancer report their major concern is their family's well-being [5]. When a parent or child is diagnosed with cancer, family members experience fear of losing the loved one and of the suffering she/he likely will experience [7]. Adolescent children of a parent with cancer are in a particularly vulnerable phase in their development and often experience severe emotional distress and fear a parent will die. Changes in roles and expectations may require adolescents to take on extra household responsibilities and in the care of their siblings. Not knowing how to react to these new situations or a parent's depressed mood, children may develop behavioral problems [6].

In addition to coping with physical and psychological reactions to having cancer, parents experience additional stressors when they are limited or unable to maintain usual involvement in the lives of their children. Hospital and primary care staff, who gain awareness of how children and the individual with cancer respond to a cancer diagnosis, are well-positioned to guide the individual, spouses and children through an emotionally stressful time [8].

In one study of men diagnosed with prostate cancer, couples of working age (age 50–64) experienced more disappointment and anger of getting cancer than couples who had retired [9]. Potentially having much unaccomplished in life, people who were part of the workforce are more reluctant to accept the implications of having cancer than are people of an older age. Financial issues become stressful as the treatment of prostate cancer affected the husbands' ability to work and to carry out tasks he previously performed on a daily basis [9].

Financial issues may impact the dyadic relationship of couples in a variety of ways. In a study by Harden et al., [9] couples expressed that "Being in it together" was important, and working spouses were unhappy for not being able to accompany their partner to medical appointments and treatment:

I couldn't be there for all his treatments because I had to work (...) because if I lose my work, I lose our insurance and possibly our house. So it was important for me to work, but it was hard. I just had to be strong and keep things going. [9, p. 372]

The need to work while at the same time wanting to be with her husband during treatment exemplifies the difficulty of balancing employment and care demands. Family caregivers often face this challenge and the result may be a need to reduce work hours. A reduction of work hours may impact family health insurance and retirement benefits [10].

Factors Related to Return to Work

Looking across the relatively few studies conducted focusing on work and return to work among individuals with cancer, Spelten, Sprangers, & Verbeek identified three main categories of factors motivating employment status: (1) work-related, (2) disease- and treatment-related, and (3) person-related. We discuss these in detail [11].

Work-Related Factors

There may be many reasons why people continue working during treatment, despite the fatigue, nausea, and other side effects of treatment. Fear of being fired or being repositioned to a lower status job are factors impacting one's decision to keep on working but work may also provide a source of social support facilitating recovery and long term adaptation to this life threatening experience. In one study by Main and colleagues [12], addressing patterns of work return and factors influencing post-cancer decisions among 28 persons with diverse cancer diagnoses, participants emphasized the importance of holding on to the job because it helped them take their mind off the cancer. One study participant explains the significance in these terms: "You forget about whatever else you're doing. It's not a support group. It's not acupuncture; it's not your appointments. It's something totally away from cancer" [12, p. 997]. To some, work represents an important social arena where the person with cancer meets people outside the family and treatment sphere [12].

There's days when I want to go in there and just say you know 'I can't do this no more', but then I'm afraid of doing that because sometimes just being in there 1 or 2 days a week . . . really helps with my mental ways of thinking and just not being stuck in the house . . . It kind of lifts your spirit [12, p. 997].

These experiences corroborate the findings of Spelten and colleagues that a return to work may be associated with social support [11].

Two core factors are identified to impact work return—the nature of the job itself and the attitudes and culture in the organization. A supportive work environment or culture is found to facilitate a return to work, while manual work and work settings that require strong physical effort represent impediments [11]. In addition, the positive attitudes of employers and colleagues, and toward flexible or reduced working hours (i.e., workplace accommodations), are important elements of a supportive work environment [13, 14].

Study-participants in the Main study narrate on employers' flexibility during treatment [12]. One study-participant recounts: "[The employer] said 'Go on home if you don't feel good. Go home.' And they saved my job, like I said, for months so I could go back." [12, p. 1000] Others were reassigned tasks: "I had been traveling for 13 years. At least 9 months of the year I would be on the road Monday through Friday. When I came back, they said, 'No, you're not going to travel. You need to be close to your family'" [12, p. 1000]. In another study, one woman reports: "My employer was very understanding about the days missed each month when I had my chemo and the few days I took off because I was too nauseated to be there" [5, p. 661].

Disease and Treatment-Related Factors

The likelihood of returning to work increases with the time passed after the completion of treatment [11]. Nevertheless, some persons with cancer undergoing treatment keep on working [12]. Fatigue during and after treatment often is reported by individuals with cancer as explained by one study participant: "I was doing chemo and . . . my energy wasn't good—you don't want to do anything. I was just really tired" [12, p. 997]. A profound feeling of fatigue is the most frequently reported manifestation of cancer treatment and often severely impacts everyday activities of the individual with cancer [7]. However, other common outcomes from treatment may include short or long-term lack of upper body strength, memory loss, and constant pain [15].

Person-Related Factors

Other motivational factors are not related to a work return [11]. Being diagnosed with a serious, sometimes life-threatening disease, may contribute to a scrupulous self-reflective period where existential questions are raised. Subsequently, a change in work attitude may emerge, such as feeling less inspired to work [11]. In a study by Edbril and Rieker [16], the significance of working after being diagnosed with testicular cancer decreased for some study participants because they realized that life is too short to be so involved only in work.

Studies show mixed results with respect to a positive or negative association between return to work and the type of cancer [11]. In one study on a heterogeneous group of individuals with cancer, those reporting the most problems on work return are individuals with head, neck and breast cancer [11, 17]. In another study, the problems experienced by persons with head and neck cancer of returning to work are also identified, while men with testicular cancer report few problems and have a high return to work rate [11, 18]. The findings of a recent study on work return among women with breast cancer identify a high return rate [19]. Compared to the study by Weis et al. [17], the recent study's findings may be explained by improvements in treatment and follow-up care, also experienced by a person with cancer: Brooks was first diagnosed with breast cancer in 1991 [4]. She recovered, but 14 years later another tumor was

found. This time "the treatment I received was excellent, and I had much more support and information provided than in 1991. Because of better awareness on my part and prompt attention from the clinicians, this tumor was diagnosed earlier (grade I) and required no further treatment, other than drugs" [4, p. 33].

Overall, these accounts show the importance of supportive employers and flexible work schedules. Knowing employment is not only important as a realm where one makes use of one's competence, but also for a person's income, inclusiveness provided by the employer is significant for ensuring that more working age persons with cancer do not stop working. Moreover, as most people in the United States obtain their health insurance through employers, the loss of a job because of cancer impacts the person's health insurance coverage and income [7].

Some people with cancer experience non-inclusive work environments and face attitudinal discrimination. According to a recent study analyzing ADA claims among individuals with cancer and non-cancer related impairments, "job termination and terms of employment are more likely to be concerns for employees with cancer than employees with other types of impairments" [3, pp. 185-186].

Federal Protections for the Employee with Cancer

Persons who have or acquire a physical or mental impairment, a serious health condition, or a chronic illness enjoy protections from discrimination by employers and insurance companies, and in the workplace on the basis of these conditions. The Americans with Disabilities Act of 1990 (ADA) prohibits employers with 15 or more employees from discriminating against qualified employees with disabilities in "job application procedures, the hiring, advancement, or discharge of employees, employee compensation, job training, and other terms, conditions, and privileges of employment" [20]. The qualified employee is one who can perform the essential functions of the position with or without reasonable accommodations, and who has a substantial limitation in a major life activity [20].

While ADA Title I applies to the employment realm, the Family & Medical Leave Act (FMLA) provides for a person to take up to 12 weeks of unpaid medical leave per year for a serious medical condition [21]. It also allows for up to 12 weeks of unpaid leave to care for a seriously ill spouse, parent or child [21]. Although unpaid, the employee returns to the same or an equivalent position after the leave, and the employer is required to keep an employee's benefits intact [21].

Two additional federal laws provide health coverage security beneficial to an employee with cancer. The Health Insurance Portability and Accountability Act of 1996 (HIPAA) prohibits group health plans from excluding coverage based on pre-existing medical conditions covered under a previous creditable

plan [22]. HIPAA also protects covered employees and their families from losing health insurance if the employee changes jobs [23]. The Consolidated Omnibus Budget Reconciliation Act of 1986 (COBRA) allows an employee to continue the same health insurance coverage the employee received through their former employer for a period of 18 months after leaving the position, being terminated, or reducing work hours [23]. We discuss these protections in detail below.

The ADA

The Americans with Disabilities Act of 1990 (ADA) passed with bipartisan support and was signed into law by President George H.W. Bush to provide people with disabilities the right to be judged with fairness and equality. President Bush hailed the ADA as "the world's first comprehensive declaration of equality for people with disabilities" [24]. This landmark civil rights law prohibits discrimination against persons with disabilities in the workplace, public accommodations, and by state and local government [25].

A cancer diagnosis, like any impairment or illness, is not per se a disability covered by the ADA. Cancer is considered a disability under the ADA when its effects, or the side effects of treatment, substantially limit one or more major life activities [20]. For instance, a person may experience depression as a result of cancer, thereby substantially limiting their sleeping or eating for an extended period [1]. Cancer also may be a disability if it substantially limited the employee in the past or if the employer incorrectly regards the employee as having a substantial limitation [20]. To determine if cancer is a disability as defined by the ADA, courts analyze each claim on case by case basis [1].

The ADA requires employers provide reasonable accommodations for employees with disabilities to assist them to perform essential job functions and ensure they have equal access to the facilities, programs, and benefits of the job [20]. Reasonable accommodations include making workplace facilities "readily accessible to and usable by individuals with disabilities," restructuring a job, modifying schedules, equipment and policies, acquiring assistive technologies, adapting training materials, providing qualified interpreters, and many other possibilities [20, 26]. Making a reasonable accommodation requires an individualized inquiry specific to the employee, the disability, job requirements, and other relevant factors [25]. Employers should be aware that not all individuals with cancer require accommodations, and two employees who have the same type of cancer may need different accommodations [1].

For instance, employees with cancer may request leave time for doctor's appointments or weekly treatments. They may ask for extra breaks during the work day to rest or to take medications. The employee with cancer may benefit from an adjustment in the work schedule while attending cancer treatments. Some employees may request to work from home for a temporary period. The

employer and employee are encouraged to engage in an interactive process to make well-informed decisions about accommodations that will work best for both the employee and employer¹ [27].

Some employees feel shame, fear, uncertainty, or embarrassment when discussing their cancer diagnosis with an employer [28]. However, if an employee with cancer wishes to receive accommodations they need to let the employer know of the need, as only disabilities known by the employer require accommodations [20]. Requests for accommodation may come from friends, family members, or doctors. Some employees prefer a doctor to write a request for accommodation because it may carry more weight in the employer's mind [1].

Employers may request medical documentation after an employee has requested reasonable accommodations at work [27]. Employers only may view relevant medical documentation that will help formulate an accommodation plan [1]. Employers do not have to grant every accommodation request; they only must provide "reasonable" accommodations that do not impose an undue hardship [20]. Undue hardships are determined on an individual basis when an employee requests an accommodation, and requires a showing of "significant difficulty or expense" in light of the employer's overall resources [20].

In addition to protecting people with disabilities from discrimination, the ADA protects individuals, with and without disabilities, who are discriminated against because of their known association with an individual with a disability. The "associational discrimination" protection is not limited to those with a familial relationship with an individual with a disability, but also may include business, social, and care giving relationships. The protection means that, if an employer denies a job benefit (e.g., health insurance coverage) to an employee with a family member with cancer covered by the ADA, the entity may be liable for discrimination [25].

Other Federal Protections

The FMLA applies to employers with 50 or more employees [32]. Employees must have been employed at least a year and have worked a minimum of 1,250 hours in that year [32]. Sometimes, a person will need more than the 12 weeks of leave provided by the FMLA. In this event, a person may be able to take additional leave time as a reasonable accommodation under the ADA [32]. Alternatively, some states provide greater protections, such as requiring less employed hours in the year for initial FMLA leave eligibility and do not have a proviso for the number of employees within the specified radius of the

¹ Though the ADA encourages use of an interactive process, some courts have held it is required [29-31].

workplace.² Employment law attorney Loring Spolter provides a seven item "FMLA Checklist" to "minimize difficulties and preserve legal rights" under the FMLA [33]. The checklist addresses issues of documentation, requesting leave and extended leave, and quality of communications, among others.

Briefly mentioned above, COBRA allows an employee to continue the same health insurance coverage received through a former employer for up to 18 months after a reduction in work hours or leaving employment (including termination). However, the employee is responsible for paying the premiums [23]. COBRA applies to employers with at least 20 employees [22], though many states have similar laws covering employers with fewer than 20 employees³ [34].

Under HIPAA, the employee receives "creditable coverage" for the period she previously had health insurance. Creditable coverage travels with them when they go to a new employer and is credited towards any pre-existing condition exclusions [22]. HIPAA limits the amount of time a pre-existing condition may be imposed (12 month maximum) and applies a 6-month limit on how far back an insurer can look at an applicant's health history for purposes of imposing a pre-existing condition exclusion [22]. HIPAA further permits a person to transfer from the group health plan to an individual health plan when meeting certain conditions, such as not having a break in health insurance coverage longer than 63 days [22]. State laws may provide greater protections [22].

Privacy and Confidentiality

Employers must keep all medical documentation and knowledge of an employee's diagnosis confidential. The only exceptions to the confidentiality rule are: (1) when employers need to inform the employee's supervisors to facilitate proper accommodations for the employee; (2) if worksite medical staff need to know of a possible disability-related emergency (e.g., fainting at work); and (3) if government officials require relevant information to investigate compliance [27].

The ADA strictly limits the circumstances under which employers may ask medical related questions of an employee with cancer. Employers are allowed to ask an employee to undergo medical testing if the employer has a reasonable concern that the employee's diagnosis is affecting the ability to perform the job [20]. For instance, an employer may ask an employee to have a medical evaluation when the employee seems to experience fatigue constantly at work, and the

² The U.S. Department of Labor offers a complete list of these states and their comparative protections [35].

³ For example, Cal-COBRA in California covers employers of 2-19 employees and the Massachusetts Small Employer Health Reinsurance Plan covers employers of 1-50 employees [36, 37].

employer has a legitimate reason to believe they are unable to perform their job [27]. Employers must be careful not to request a medical exam if they only notice insufficient job performance, which may arise from a wide variety of non-health or disability related factors [1].

Furthermore, employers are permitted to ask an employee on medical leave for cancer treatment to submit medical documentation prior to returning to work [20] and clarifying their ability to return to work [32]. Employers are only entitled to medical documentation of an employee's present work ability and not their future work abilities [1].

The Story of Patricia Garrett

The story of Patricia Garrett, an experienced nurse working for the University of Alabama at Birmingham hospital ("University"), is a 13-year legal saga in which federal laws and courts failed an individual with cancer subject to discrimination on the basis of her illness. Ms. Garrett was a supervising nurse at the University when in August, 1994 she was diagnosed with breast cancer. She took time off for a series of treatments and returned to work full-time in September of that year. Due to her ongoing treatments, Ms. Garrett requested and received intermittent medical leave over the next year [38].

At work, Ms. Garrett was able to complete all of her duties with accommodation. Radiation therapy caused burns to her right arm that limited her lifting ability. She needed extra time and had to take frequent breaks due to fatigue. At home, she could not perform ordinary household tasks such as cleaning, laundry, and cooking, and it took her twice as long to complete her self-care tasks. In January 1995, she was hospitalized for an infection, and took medical leave again in March as an accommodation. She returned to work in July of that year. Two weeks later, she was transferred to a lower-paying position at a different University facility [39].

State Sovereign Immunity

Ms. Garrett originally brought suit in January, 1998 in the federal district court for the Northern District of Alabama under the ADA, the Rehabilitation Act of 1973, and the FMLA. The district court dismissed all three claims on the basis of state sovereign immunity [40]. The principle of sovereign immunity arises from the Eleventh Amendment to the U.S. Constitution, and protects state autonomy by immunizing states from suits in federal court by private citizens seeking money damages or other equitable relief [41].

Between 1998 and 2005, Ms. Garrett was embroiled in a dispute between the federal district court, the Eleventh Circuit Court of Appeals, and the U.S. Supreme Court over what conditions and under what federal laws a state

affirmatively waives its sovereign immunity.⁴ Two important decisions arose from the nine court decisions over the seven years. In 2001, the U.S. Supreme Court concluded the legislative record of the ADA failed to show Congress identified a pattern of state discrimination in employment against persons with disabilities. Hence the Supreme Court did not support abrogating the states' sovereign immunity under the ADA [41].

Then in 2003, the Eleventh Circuit concluded the University had waived its sovereign immunity under Section 504 of the Rehabilitation Act by accepting federal funds [42]. This ruling was important for plaintiffs for whom injunctive relief (e.g., the court ordering the University to give Ms. Garrett her job back) would not be effective. In Ms. Garrett's case, her previous job was no longer vacant, and she did not wish to return to a work environment she considered hostile [39]. Notably, twelve of the thirteen U.S. Circuit Courts of Appeals⁵ agree that when a state voluntarily accepts federal funds, and is aware if it were to violate a federal statute that expressly waives state sovereign immunity, including Section 504, it will have waived its sovereign immunity to suit under that statute [46–57].

Qualified Individual with a Disability

The *Garrett* case was remanded once again to the federal district court and decided in January, 2005. The district court held that (a) Ms. Garrett's transfer to a lower-paying position was not an adverse employment action under the Rehabilitation Act; (b) Ms. Garrett was not a "qualified person with a disability"; and (c) Ms. Garrett's transfer did not constitute retaliation under the Rehabilitation Act [45]. She appealed to the Eleventh Circuit to determine whether because she requested and took medical leave for breast cancer treatments that limited her work performance (1) she was a qualified individual with a disability, and (2) the University made a retaliatory adverse employment

⁴ To clarify, in 1999 on appeal, the Eleventh Circuit Court of Appeals reversed the district court decision holding the ADA and the Rehabilitation Act effectively abrogated state sovereign immunity [38]. On appeal in 2001, the U.S. Supreme Court overturned the Eleventh Circuit decision (discussed below) [41]. Later that year, the Eleventh Circuit ordered the district court to determine whether the State's receipt of federal funds waived its sovereign immunity for purpose of enforcing Section 504 of the Rehabilitation Act (providing substantially the same protections for an employee as the ADA) [43]. On remand, in 2002 the district court held state sovereign immunity was not waived under Section 504 [44]. In 2003 on appeal, the Eleventh Circuit reversed the district court's decision in this respect and ordered the court to determine whether the State had violated Section 504 [42]. The district court concluded Ms. Garrett was not a qualified individual with a disability and thus not entitled to Section 504 protections, and the Eleventh Circuit affirmed in 2007 [39, 45].

⁵ The Court of Appeals for the Federal Circuit, which generally hears only specialized cases, has not addressed the issue.

action by transferring her to a lower-paying position in violation of the Rehabilitation Act [39].

Ms. Garrett argued she was a qualified individual with a disability. The parties did not dispute that she was qualified for her positions or that she had breast cancer. Ms. Garrett contended that she was substantially limited in the major life activities of caring for herself, ordinary household chores, lifting, and working because of the side effects from her cancer treatments. The court, however, determined her limitations (a) were temporary because they were simultaneous with her treatments, (b) were not present at the time of the alleged adverse employment action, and (c) were not sufficiently limiting in any major life activity to qualify as a disability [39].

Ms. Garrett argued the University retaliated against her because she requested and took intermittent medical leave for cancer treatments. To make this claim, Ms. Garrett had to demonstrate she (a) engaged in a protected activity, (b) suffered an adverse employment action, and (c) the protected activity was causally connected to the adverse employment action. The court assumed that making a medical leave request was a protected activity [39]. Ms. Garrett principally argued that the University demoted her on July 21, 1995 by transferring her to a lower-paying position in retaliation for her March 1, 1995 request for medical leave, which she took until July.

The University argued Ms. Garrett requested the transfer and, therefore, the lower pay, transfer, and approval of Ms. Garrett's request were legitimate, non-retaliatory, and non-discriminatory. There remains a genuine issue of material fact (i.e., disagreement) whether Ms. Garrett was demoted or voluntarily transferred to a lower-paying position. Nonetheless, the court determined that Ms. Garrett failed to show a causal connection between her request for leave and her transfer, because the timing of the leave request and the transfer were too far removed (over 4 months) "in the absence of other evidence tending to show causation" [45, p. 1251]. On November 15, 2007, the Eleventh Circuit affirmed this decision, and likely closed the book on the *Garrett* case.

Individuals with Cancer in Other Courts

Employment discrimination against qualified individuals with cancer takes a toll on society. Individuals with cancer report higher rates of employment discrimination including lost wages, unfair stereotyping, and unreasonable termination [3, 58]. Consequently, it is worth considering how the ADA has been interpreted by different courts to protect employees with cancer.

Individuals with cancer often claim their employer violated Title I of the ADA by failing to provide reasonable accommodations [59]. For individuals with cancer to succeed in a failure to accommodate claim under the ADA they must prove: (1) they are a qualified individual with a disability; (2) their employer is aware of the disability; and (3) their employer failed to reasonably

accommodate their disability [20]. To satisfy the "qualified individual" prong, employees must show they have the proper training and skills to perform a certain job, and they can perform the essential job functions with reasonable accommodations if needed [20]. Attendance is considered an essential function for many jobs,⁶ and people who need time off for cancer treatments may find difficulty attending work regularly.

A larger hurdle than acquiring an accommodation, however, often is showing the person with cancer has a covered disability. To invoke the ADA's basic protections, recall that a plaintiff must show he or she is substantially limited in a major life activity, has a record of this limitation, or is regarded by his/her employer as such (whether or not accurate) [25]. The Eleventh, Ninth, and Fifth Circuit Courts of Appeals have concluded plaintiffs with cancer were not substantially limited in the major life activity of working. These courts found cancer did not substantially limit the plaintiffs' "work activities" [60]. In *Gordon v. E.L. Hamm & Associates* [61], the Eleventh Circuit stated although the side effects of chemotherapy may constitute a disability under the ADA, they did not substantially limit the plaintiff in that particular case. The court reasoned the plaintiff's ability to work through the chemotherapy without requiring hospitalization, and the plaintiff's concession he carried on life in a normal manner, proved he was not substantially limited in the major life activity of working.

Similarly, the Fifth Circuit narrowly interpreted the ADA in *Ellison v. Software Spectrum* [62], and held a woman with breast cancer was not a qualified person with a disability because she was not substantially limited in the major life activity of working. The court reasoned her ability to continue working on a modified schedule, and to perform the essential functions of the job despite feeling sick, failed to demonstrate she was substantially limited. The court further concluded Ellison did not have a record of disability and was not regarded as having a disability by her employer.

In *Sanders v. Arneson Products, Inc.* [66], the Ninth Circuit concluded the plaintiff's psychological difficulties arising from cancer diagnosis and treatment did not qualify as a disability under the ADA. The court quoted the ADA's implementing regulations stating "temporary, non-chronic impairments of short duration, with little or no long term or permanent impact, are usually not disabilities" [66, p. 1354]. In each of these cases the courts focused on the individual's response to cancer and their ability to perform in spite of the disease and/or treatment.

Furthermore, some courts are inclined to view cancer as not typically substantially limiting any major life activities or otherwise constituting a disability for purposes of the ADA. In *Schwertfager v. City of Boynton Beach* [67], the federal district court for Southern Florida concluded a woman with breast

⁶ For instance, insurance agent must be available to drive to accident sites [63]; Software Quality Engineer must have regular and reliable attendance at project, process, staff, and 1:1 bi-weekly meetings [64]; Dockworkers must be on site to perform basic duties [65].

cancer had no record of a disability, despite her diagnosis, hospitalizations, anatomical loss and treatments, because the record did not indicate she ever had been substantially limited by the cancer or treatments. Furthermore, the court concluded her employer did not regard the cancer to be "significant" [67, p. 1360-1361].

In *Hirsch v. National Mall & Service Co.* [68], the federal district court for Northern Illinois held a man was not a person with a disability under the ADA, despite being terminally ill with cancer. Mr. Hirsch was a 32-year veteran of National Mall & Service, a vending machine distributor. He was terminated to cut health care costs after informing his employer he had advanced lymphoma. His wife brought suit under the ADA on his behalf because he passed away shortly after losing his job. The court reasoned there was no evidence of impairment in Mr. Hirsch's daily work activities, and that his employer did not regard him as having a substantial limitation.

There is reluctance on the part of courts to find that cancer is a disability. The *Hirsch* and *Schwertfager* decisions demonstrate the uphill battle people with cancer have in proving a "record" of disability or that they are regarded as having a disability. This is in addition to the frequent challenge persons with cancer face demonstrating they are presently substantially limited because effective treatments can make cancer too temporary to qualify as a disability [15]. In contrast, research discussing prostate, breast and other cancers find that substantial limitations from surgery or treatments may continue for many years [15, 69-70].

Moreover, Farley-Short, Vasey, and Belue concluded because cancer treatments are so strenuous, cancer survivors "suffer from [disabilities] and/or work limitations at a higher rate than individuals with other chronic diseases" [69, p. 97]. Courts also may consider a limitation of greater severity to outweigh the absence of long-term effects [71]. Liu argued courts are given too much latitude to determine what "substantially limited" means, making it difficult for individuals with cancer to predict success in court under the ADA [60].

Best Practices and Future Initiatives

In the United States, there are 52 million people with disabilities and 11 million people with cancer [72]. As the treatment and survival rates for cancer improve, there are more people who decide to remain at work during treatment or who return to work after treatment is concluded [11]. A cancer diagnosis may carry a variety of potential legal issues, including employment discrimination, health care coverage, confidentiality, access to government benefits, and estate planning. These legal issues may cause unnecessary worry, confusion, and stress. When not addressed, people may find themselves surviving the disease yet losing their jobs and income, health coverage, and homes and families [58].

Model Programs and Services

There are a number of model programs and services in existence that educate employees about their legal rights in the workplace and teach employers about their legal responsibilities. In 2002, the Cosmetic Executive Women Foundation developed the Cancer and Careers program to change the face of cancer in the workplace by providing a comprehensive website, free publications, and a series of support groups and educational seminars for employees with cancer [73]. The Foundation sponsors the "Managing Through Cancer" program to provide employers, managers, and HR professionals with clear direction, resources, and concrete tools to maintain a fully productive workplace while proactively supporting their employees with cancer [74]. Tools include tips on what to say, templates for implementing flexible work arrangements, and a set of principles that may serve as a company's commitment to support employees with cancer, company-wide [75].

The Cancer Legal Resource Center (CLRC) provides information and resources on cancer-related legal issues to persons with cancer, their families, friends, caregivers, employers, health care professionals, and others coping with cancer [76]. The CLRC is a joint program of Loyola Law School and the Disability Rights Legal Center (DRLC) in Los Angeles, California. It was created to address the fact that while there were many cancer-related resources available for medical care and psychosocial support, there was nowhere to turn to get assistance with cancer-related legal issues [77]. Prior to contacting the CLRC, many people do not realize they qualify for protections under various laws because of their diagnosis [78].

The CLRC hosts a toll-free, national Telephone Assistance Line (866-THE-CLRC), staffed primarily by law students under staff attorney supervision. In 2007, the line received almost 4,000 calls addressing a variety of legal issues (for distribution of calls, see Fig. 12.1 below) [79]. The students educate the callers about cancer-related legal issues, while learning about the pertinent laws and dynamics of providing legal assistance to people with cancer [79]. The CLRC has received an increasing percentage of its calls from outside of California.⁷ This increase may be attributed to the CLRC's partnerships with national cancer organizations, such as the American Cancer Society and the Lance Armstrong Foundation [79].

Over the last ten years, twenty percent of calls to the Telephone Assistance Line have addressed employment-related issues, such as (1) when persons are recently diagnosed and need information on working with their employer while they receive treatment; (2) receiving negative employment evaluations after disclosing their medical condition; (3) losing their job and requesting alternatives options; and (4) returning to the workforce and whether they should disclose to a potential employer [80]. In the last five years, the CLRC has

⁷ In 2002, 40%; and in 2007, 56% [80].

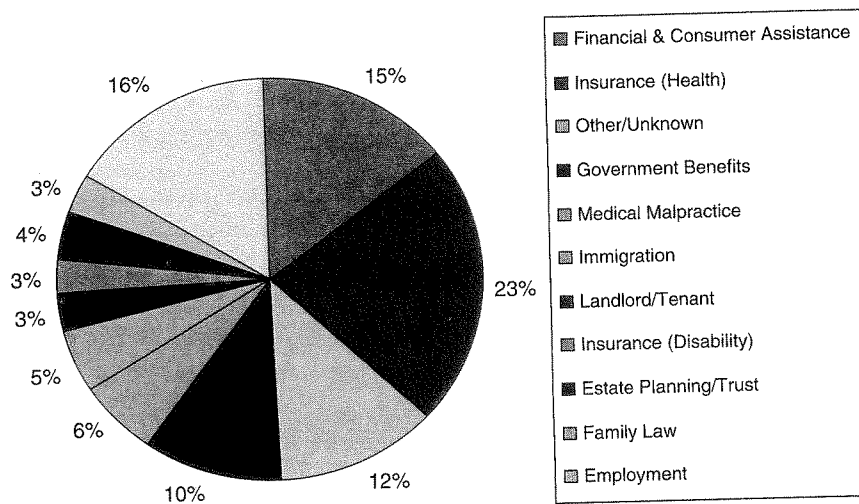


Fig. 12.1 2007 Telephone assistance line calls – legal issue

received over 1,000 calls from employees who believe they were terminated as a result of their cancer diagnosis [81].

The CLRC trains front-line oncology health care professionals to identify the presence of cancer-related legal issues for their patients, and to effectively advocate for people with cancer [77]. On April 19, 2007, the CLRC received its 20,000th call to its national Telephone Assistance Line [79]. Throughout its 11-year history, the CLRC has reached over 90,000 people through the Telephone Assistance Line, conferences, seminars, workshops, outreach programs, and other community activities [79]. When people need more than information about their legal rights, the CLRC refers individuals to an extensive national network of volunteer attorneys [79].

ADA Amendments Act of 2008 and the Future

Several decisions of the U.S. Supreme Court eroded protections the ADA provides to people with cancer, diabetes, epilepsy, and other chronic disabilities. [82–84] Courts have concluded people with cancer are too healthy to have a disability and, therefore, are not entitled to protections under the ADA. [62] After the U.S. Supreme Court decided *Sutton v. United Air Lines Inc.* in 1999, [85] a person's ability to mitigate the effects and limitations of a disability had to be considered when determining whether they have a substantial limitation. Consequently, individuals with cancer who mitigate or eliminate the limitations caused by cancer treatment often did not have a disability that meets the definition under the ADA.

When people with cancer undergo treatment, they often take medications that alleviate the side effects of treatment, such as nausea or fatigue. [86] In so doing, they may feel better, but they also may mitigate a substantial limitation to a major life activity. Without a substantial limitation, following the *Sutton* ruling, they were no longer entitled to protections under the ADA. An absurd “catch-22” was created where these individuals had no form of redress, even when told explicitly they were not hired or were terminated because of their disease. [58,62] For example:

- Mary is a 26-year old woman from California with a brain tumor. She worked for a small employer of 15 employees. Her employer terminated her after she requested time off to attend a doctor’s appointment to address complications from her cancer treatment.
- In Utah, Trudy, age 39 working for a large national employer, was diagnosed with breast cancer. She wanted to continue working during her treatment, but her employer fired her after missing too many days of work.
- Robert, a 57-year old man from California and vice-president of a real estate company, was diagnosed with colon cancer. He took six weeks of medical leave to undergo surgery and treatment and was promptly terminated the day after he returned to work.
- Melanie, a 37-year old woman in Georgia diagnosed with lung cancer, was terminated from her job with a federal bankruptcy court after being told she was “difficult” when she asked for accommodations, such as turning down the heat in the office. [81]⁸

There are thousands of people like Mary, Trudy, Robert, and Melanie, who are willing and able to work, yet are discriminated against on the basis of disability because of a serious health condition. These incidents are the kind of blatant, workplace discrimination and prejudice the ADA was intended to stop. [87] Yet these people—and many in their situation—have not been protected by the ADA, resulting in devastating consequences for people who are not only battling cancer (and for their families), but also struggling to stay afloat financially. They may have residual symptoms from their diagnosis or treatment and may find it difficult to search for a new job; they may face the loss of health insurance or foreclosure on their homes, and too often, personal bankruptcy. [58]

On July 26, 2007, House Majority Leader Steny Hoyer, Congressman Jim Sensenbrenner, and Senators Tom Harkin and Arlen Specter introduced draft bills to enact the ADA Restoration Act of 2007 (subsequently called the “ADA Amendments Act of 2008”), aiming to restore the ADA to its original intent and effectiveness. In a press conference introducing the original House bill, Congressman Hoyer noted, “the Supreme Court has improperly shifted the focus of the ADA from an employer’s alleged misconduct, on to whether an individual

⁸ Some names have been changed to protect the privacy of the individuals.

can first meet—in the Supreme Court’s words—a ‘demanding standard for qualifying as disabled.’” [88]

On, September 25, 2008, President George W. Bush signed Senate Bill 3406, the ADA Amendments Act of 2008, into law [89]. The Amendments assertively depart from Supreme Court decisions that severely limited the ADA’s protected class, placing the focus on whether a person is qualified for the job, and minimizing the focus on the level or type of impairment. Specifically, the Act precludes courts from considering mitigating measures. Additionally, the Amendments will protect people episodic conditions or when in remission, if the condition does limit a major life activity when active [90].

There remains opposition from business entities and others who fear the Act will increase litigation. [91] There also is concern in the disability community that the Act will compromise existing protections in the law. On its face, the proposed Act does not seek to expand the rights guaranteed under the original landmark ADA. Instead, it seeks to clarify the law, restoring the scope of protection available under the ADA; it responds to court decisions that have restricted the class of people who may invoke protection under the law, and reinstates the Congressional intent behind the ADA. [90]

Recommendations and Closing Remarks

There are a number of steps to address the rights of employees with cancer in the workplace. First, and most importantly, it is crucial that people with cancer understand their rights under the ADA and other federal laws to navigate challenging workplace issues. This requires extensive consumer outreach and increasing consumer education programs and services, such as provided by the CLRC and the Cancer and Careers program.

Second, stakeholders such as business owners and the U.S. Small Business Administration require further training and technical assistance to improve compliance with the law. The EEOC and their state level counterparts are well-positioned to address this need. Funded research and technical assistance centers including the Job Accommodation Network and the Southeast ADA Center extensively engage in these education and outreach initiatives [26, 92]. These entities and others work with chambers of commerce and human resource staff and associations to create an effective educational campaign for employers and employees with cancer on their legal rights and responsibilities.

Third, there must be increased research and legislative advocacy to ensure that people with cancer and their family members are protected from discrimination. According to the National Organization on Disability [93], 70% of workplace accommodations may be made for less than \$500. However, more research is needed on the costs and benefits of providing employer education programs and providing reasonable accommodations specifically to people with cancer [26]. At the federal level, the enactment of the ADA Amendments

Act will reverse Supreme Court decisions and restore the intent of the ADA, to better protect individuals with cancer. At the state level, legislatures may enact stronger protections from all discrimination "on the basis of disability," rather than against only persons with a substantial limitation in a major life activity. Together, these steps are important for educating employers and the public about the true capacities and needs of people with cancer.

Acknowledgment Peter Blanck, Ph.D., J.D., Chairman, Burton Blatt Institute (BBI), University Professor, Syracuse University (SU); William N. Myhill, M.Ed., J.D., Senior Research Associate, BBI, Adjunct Professor of Law (SU) (in loving memory of M.M., and with endearing love for E.A.M.); Janikke Solstad Vedeler, M.S., Visiting Pre-Doctoral Scholar, BBI, Research Associate, Norwegian Social Research (NOVA, Oslo); Joanna Morales, J.D., Director, Cancer Legal Resource Center, Adjunct Professor of Law, Loyola Law School (Los Angeles); Paula Pearlman, J.D., Executive Director, Disability Rights Legal Center, Associate Clinical Professor of Law, Loyola Law School. This research was funded, in part, by grants to Dr. Blanck from the U.S. Department of Education, National Institute on Disability and Rehabilitation Research (NIDRR) for (i) "Demand Side Employment Placement Models," Grant No. H133A060033; and (ii) "Southeast Disability & Business Technical Assistance Center," Grant No. H133A060094. The authors thank law students Lauren Chanatry, Janelle Frias and Ashleigh Hope, research assistant Aaron Gottlieb, and intern Erica Dolak for their research assistance.

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