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## ▣ **CAMPANELLA, ROY** (1921–1993)

*American baseball player*

Roy Campanella was one of the best offensive and defensive catchers in professional baseball in North America. After seven years in the Negro Leagues with the Baltimore Elite Giants (1937–1941, 1944–1945) and two in a Mexican league (1942–1943), Campanella joined the Brooklyn Dodgers not long after Jackie Robinson. One of the first African Americans in the major leagues, he was a leader by successful example who helped to integrate baseball. In his 10 seasons with the Dodgers (1948–1957), Campanella made the All-Star team eight times and won three National League Most Valuable Player (MVP) awards. Campanella helped the Dodgers win five pennants and the 1955 World Series. Although his Major League career was plagued by injuries, he batted .276 with 242 home runs and 856 runs batted in. In his 1953 MVP season, he led the league with 142 RBIs, batted .312, and set a record for catchers with 41 home runs.

On January 28, 1958, Campanella's car skidded on a patch of ice and crashed into a telephone pole. He broke his back between the fifth and sixth vertebrae and was paralyzed from the chest down. Through physical therapy Roy learned to move his arms and hands, feed himself, and use a wheelchair. On May 7, 1959, "Roy Campanella Night" was held at the Los

Angles Coliseum with record attendance of 93,103 fans. In 1964, he began working as a catching instructor for the Dodgers and was inducted into the Baseball Hall of Fame in 1969. In 1978, he joined the Dodgers Community Service team and was active in providing support for youths with disabilities. He worked and spoke for the Dodgers and on disability issues until he died of a heart attack on June 26, 1993. The Roy and Roxie Campanella Physical Therapy Scholarship Foundation provides support to physical therapy students whose cultural competence and ethics aid patient well-being.

—*Daniel J. Keys, Christopher B. Keys, and Robert I. Westerholm*

*See also* Paralysis; Sports.

### **Further Readings**

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## ▣ **CANADA**

*See* Disability Law: Canada

## ▣ CANADIAN CENTRE ON DISABILITY STUDIES

The Canadian Centre on Disability Studies (CCDS) is a nonprofit, consumer-directed, university-affiliated center dedicated to research, education, and information dissemination on disability issues. Using a participatory approach to research, CCDS promotes full and equal participation of people with disabilities in all aspects of society. Members of the disability community are key participants in directing CCDS activities: 51 percent of the CCDS Board of Directors are designated persons with disabilities.

Housed in Winnipeg, CCDS works in concert with academics, government, and the disability community. CCDS has participated in the development of an interdisciplinary graduate program in disability studies at the University of Manitoba and is currently working in partnership with the University of Winnipeg to develop an undergraduate interdisciplinary degree in disability studies.

Research by CCDS is known nationally and internationally, with projects in Russia, Mexico, Ukraine, and Thailand. In 2002, the Canadian International Development Bank announced the approval of the Canada-Russia Disability Program, a four-year, \$4 million project, focusing on education, disability studies, social work practice, social policy, and information dissemination. CCDS is involved in a variety of innovative projects such as the Arts Ability Project and the Pan-Canadian Leadership Project—Creating Opportunity and Sharing Knowledge: Leadership Development in the Canadian Disability Movement, which takes a social rather than medical approach to integrative programming.

—Gwendolyn Friedrich

*See also* Disability Studies; Research.

### Further Readings

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### Websites

Canadian Centre on Disability Studies, <http://www.disabilitystudies.ca>

## ▣ CANCER

Some nine million people living in the United States today have a history of cancer. These people, of course, do not have a universal disability, though cancer is clearly associated with a range of physical, psychological, and other disabilities. When all cancers are combined, 62 percent of the people diagnosed with cancer in the United States will still be alive five years after the initial diagnosis. In 1996, the National Cancer Institute established the Office of Cancer Survivorship “in recognition of the large number of individuals now surviving cancer for long periods of time and their unique and poorly understood needs.”

The concepts of cancer-related disability and rehabilitation developed in the 1970s, as cancer survival rates rose and research studies started to examine the psychosocial and economic ramifications of cancer diagnosis and treatment. Issues of disability linked to cancer, however, are not always openly discussed, and this silence may have contributed to the relative dearth of knowledge about the health and disability of cancer survivors. Large cancer organizations, both now and historically, have tended to downplay discussion of disability to focus on hopeful, positive messages for those diagnosed with the disease. Many of the now ubiquitous cancer fund-raising feats of physical endurance, from walks to runs to mountain climbs, are done “for the cure” and display celebratory, athletic images of winning cancer survivors. An emphasis on survivorship and returning to normality can overshadow those with long-term disabilities.

Physical disability and rehabilitation needs vary greatly with the type of cancer, the choice of treatment, and the extent to which normal functioning is affected. Cancer resulting in loss of a limb has long been recognized as an obvious disability. But a person with colon cancer may need a colostomy, a person with prostate cancer may experience sexual dysfunction, or a person with head or neck cancer may lose the ability to speak. Cancer treatments, including surgery,

chemotherapy, and radiation, are often debilitating and difficult, with some treatments themselves resulting in long-term disabilities. Physical, emotional, psychological, sexual, and financial problems can persist for years. On a more practical note, cancer survivors may have difficulties obtaining health and life insurance coverage or experience employment discrimination.

## CANCER SURVIVORS AND DISABILITY

National Cancer Survivors Day was founded officially in 1988 with a goal of demonstrating “that a diagnosis of cancer is not an automatic death sentence.” Since then, the term *cancer survivor* has permeated the national vocabulary. Typically, people who have had cancer and are now free of disease are described in popular literature not as passive cancer sufferers or victims, or even as neutral “former cancer patients,” but as active cancer survivors. *Coping*, a consumer magazine widely available in waiting rooms of oncology treatment centers, for example, instructs its writers to be “informal, upbeat and positive (assume that everyone diagnosed with cancer has a chance to beat the odds),” avoiding “grim statistics” and “lengthy treatment descriptions.” Writers are also advised to avoid the words *death*, *dying*, *suffering*, *victim*, and *patient*, substituting more positive words such as *coping* and *survivor*. As the website notes, “*Coping* challenges readers to develop a positive, proactive attitude for a better quality of life by becoming cancer survivors, rather than remaining patients and victims.” This is not the language of disability awareness.

It does not matter when the cancer diagnosis was made, or how long the cancer has been in remission, or whether any physical disability resulted; the patient is considered a cancer survivor until the end of his or her life. This lifelong association with disease and the fear of recurrence and metastasis may give cancer survivors a different psychological outlook than survivors of many other disability-causing conditions. Patients can be cured—go into remission and live cancer-free lives—but are always called survivors. Unlike many other conditions that cause disability, cancer survivors may not have obvious physical signs of their history of cancer. They do, however, continue to have higher rates of recurrence and delayed sequelae of treatment.

McNeil estimated in a 1999 study (McNeil and Binette 2001) that 792,000 adults living in the United States have been disabled by cancer, making it the 13th leading cause of disability in this country. To better understand the nature of cancer survivors’ disabilities, a 2003 study used data from more than 95,000 Americans enrolled in the National Health Interview Study. The study found that cancer survivors (as compared to people without a history of cancer) were significantly more likely to be in poor or fair health, to have a psychological disability, to have physical limitations, and to be unable to work. The researchers concluded that chance of poor health and disability are doubled by a history of cancer. In addition, cancer survivors had significantly lower self-reported measures of physical functioning, with nearly one in six (16.8 percent) of the survivors of working age saying they were unable to work due to a physical, mental, or emotional problem.

## BREAST CANCER

Breast cancer is the most common cancer diagnosis in women in the United States (excluding skin cancer) and is the second leading cause of cancer death among U.S. women. For many patients, sobering mortality and morbidity statistics combine with concerns about sexuality, mothering, or body image. Physical limitations after treatment of breast cancer can be significant, as arm mobility and lifting ability may be affected. If a woman has the lymph nodes under the arm surgically removed or radiated, lymphedema, a sometimes severe swelling of the arm caused by a buildup of lymph fluid in tissues, can result. The affected arm may swell significantly, and it will need protection from infection, cuts, sunburn, and trauma. In addition, a 2003 study by Hewitt, Rowland, and Yancik comparing long-term breast cancer survivors to women with no history of cancer found that the cancer survivors reported significantly worse sexual functioning, using indices ranging from a lack of sexual interest to an inability to relax and enjoy sex, to difficulty becoming aroused or achieving orgasm.

Historical shifts in the surgical treatment of breast cancer and the attention to emotional and psychological effects of the disease illuminate the increasing awareness of disability concerns in breast cancer. Operations that

would now be considered unnecessarily disfiguring and needlessly aggressive in removing muscles and lymphoid tissue were the standard of care for decades. In 1882, William Halsted, a professor of surgery at Johns Hopkins University, developed an operation for breast cancer that removed not only breast tissue and lymph nodes under the arm but also chest wall muscles. Eighty years later, through the 1960s, most American breast cancer patients were still treated with Halsted's radical mastectomy. This operation, however, caused considerable disfigurement and disability. Removing the muscles resulted in a deformed chest wall and limitations in arm motion, and the aggressive operation sometimes resulted in long-standing pain at the site of operation and an increased likelihood of lymphedema. But these disabling effects were considered less important in the calculus of survival, and concern over what came after surgery was downplayed.

Some surgeons turned to even more aggressive "superradical" surgeries in the years after World War II, trying to halt future spread of the disease by removing more and more tissue. In the 1960s, for example, George Pack, a surgeon at Memorial Sloan-Kettering Hospital in New York, sometimes performed inter-scapulothoracic amputations, in which he, in effect, removed a quarter of the body, taking the collarbone, scapula, and arm along with the affected breast. Other surgical procedures targeted additional lymph nodes that required rib removal and splitting of the sternum. In this manner, some surgeons caused permanent disability in their breast cancer patients. Ironically, this disfigurement was for naught. Studies eventually showed that superradical operations did not effect significant improvements in lifespan.

During these years, cancer was a diagnosis to be concealed. Stigma surrounding the disease was very high, and women typically accepted physicians' treatment plans without question. But after the mid-1970s, breast cancer entered the national dialogue, fueled in part by national figures, such as Shirley Temple Black and Betty Ford, who disclosed their own diagnoses. Some feminists saw the treatment of breast cancer as a prime example of problems within the male-dominated, authoritarian medical system. They called attention to the disability that resulted from radical mastectomies and the lack of research testing the efficacy of such aggressive operations. A modified

radical mastectomy, which removed the breast but left one or both chest muscles intact, had been developed in the 1950s, and some women started demanding this operation with a goal of reducing postoperation disability. Today, patients very rarely undergo radical mastectomies, and they often have partial mastectomies (lumpectomies), which remove only a small area of tissue around the tumor, accompanied by radiation therapy and sometimes chemotherapy or hormonal therapy. While a significant advance over radical surgery, these adjuvant treatments can also contribute to disabilities and have their own short- and long-term side effects, such as an increased risk of other cancers.

### **PATIENT-CENTERED REHABILITATION: REACH TO RECOVERY**

Individual patients played a large role in changing the system and bringing emotional and psychological issues into the medical realm. After undergoing a radical mastectomy in New York in 1952, Terese Lasser became frustrated when she received no answers to her questions: How should she obtain a prosthesis, explain her breast cancer diagnosis to her children, or return to sexual activity with her husband? As Lasser later wrote, "When told that my right breast had been removed, I wanted to shrivel up and die. How could I face life, a scarred woman? . . . How could such a life be worth living?" She worried that her husband would be repelled by her or would only feel pity for her, asking, "Was it possible for a man to desire a woman who wasn't whole?"

In time, Lasser's concerns motivated her to begin Reach to Recovery. In this program, volunteers without medical expertise who had previously undergone radical mastectomies visited and provided emotional support to hospitalized women who had just had the operation. These volunteers were encouraged to stay upbeat and positive and to dress in attractive clothing that emphasized the bustline to demonstrate that women could return to their "normal lives." The Reach volunteers gave the newer breast cancer patients temporary prosthetics, answered their personal questions, offered a "Letter to Husbands," and served as a source of information outside the medical establishment. The name of the organization came from the reaching arm exercises used to improve recovery.



Lasser had established 300 chapters of Reach to Recovery by the time the American Cancer Society took control of the program in 1969. Within five years, half of all women having mastectomies in the United States received a visit from a Reach volunteer. Today, Reach for Recovery continues its work under the auspices of the American Cancer Society with the slogan "No one should have to face breast cancer alone." The program emphasizes that its volunteers "offer understanding, support, and hope because they themselves have survived breast cancer and gone on to live normal, productive lives." Today, some 87,000 women in 44 countries are visited by 16,000 Reach to Recovery volunteers each year. In recruiting volunteers, the program asks, "Are you a breast cancer survivor who has overcome cancer to regain a well adjusted and emotionally stable everyday life?"

Reach to Recovery was one of the first programs to focus on what came after a cancer operation, using a particular psychological slant to enhance the physical recovery. Its emphasis on returning women to "normal" life, with an emphasis on continued attractiveness, was a theme that would continue in later programs. Currently, the American Cancer Society sponsors Look Good . . . Feel Better for women with all kinds of cancer. As noted on its website, the program is a "community-based, free, national service that teaches female cancer patients beauty techniques to help restore their appearance and self-image during chemotherapy and radiation treatments." This emphasis on normality and attractiveness, of course, also downplays disability awareness.

Until the 1970s, such a high percentage of breast cancers quickly killed women that reconstruction was not a priority. During that decade, however, surgery became more commonplace, and today, most women who undergo mastectomies choose reconstructive surgery.

## EMPLOYMENT AND DISCRIMINATION ISSUES

Our understanding of how a history of cancer affects workers remains incomplete. While the great majority of cancer survivors who were employed before their diagnoses return to work, they may find it difficult to

obtain or change health insurance and therefore may find themselves unable to switch jobs.

While the Americans with Disabilities Act of 1990 (ADA) does not mention cancer explicitly, the act has been used to protect cancer survivors from discrimination in the workplace. Each year, individuals with cancer or a history of cancer bring approximately 2 to 3 percent of the complaints brought under the ADA.

The Rehabilitation Act of 1973, which covers federal employees, specifically mentions cancer. It also discusses the "perception of disability," an important topic for many cancer survivors. Even if employees with a history of cancer have no physical or emotional disability from the disease, the act recognized that employers could still discriminate against them based on the perception of disability.

In 2002, cancer accounted for 4.2 percent of the total lost workdays in the United States, with an incidence of 35 days per 100 workers.

## FUTURE

Today, surgery, chemotherapy, and radiation therapy remain the main treatment options for cancer. Some breast cancer researchers have turned to genetic studies to help discover which women are more likely to respond to specific types of chemotherapy, and to modify treatments accordingly. The aggressive nature of treating breast cancer has been tempered by some measured concern over the long-term physical and psychological effects of treatment. Also, the treatments are now all less toxic.

Much is still unknown about the biology of cancer. Early detection has long been touted as the key to improving cancer outcomes, and Americans in recent years have become more willing to discuss prostate cancer and colon cancer and to undergo various cancer screening tests. When breast cancer is detected while still localized to the breast itself, 97 percent of patients will be alive five years later. If the cancer is found at the regional stage, before further metastasis, the five-year survival rate is 79 percent. Today, in part due to screening mammography, 9 out of 10 breast cancers are detected at one of these stages.

Yet early detection, while potentially limiting the amount of aggressive treatment, does not eliminate it altogether. Indeed, we should not lose sight of the

fact that lumpectomies or less toxic radiotherapy and chemotherapy still cause disability. And so, from the psychological standpoint, does any diagnosis of cancer.

—Allison Arwady and Barron H. Lerner

*See also* Breast Cancer.

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- Coping with Cancer*, online magazine, <http://www.copingmag.com/CopPages/CopAuth.html>
- National Coalition for Cancer Survivorship, <http://www.canceradvocacy.org/>
- Office of Cancer Survivorship, within the National Cancer Institute, <http://dcccps.nci.nih.gov/ocs>

## ▣ CANGUILHEM, GEORGES (1904–1995)

*French philosopher and physician*

Trained as a philosopher (at the École Normale Supérieure, 1927) and medical doctor (1943),

Georges Canguilhem devoted himself to medical practice and to the life sciences. His philosophical work was as an epistemologist. He reexamined notions of the norm, normality, and normativity.

According to Canguilhem, the normal is always secondary in relation to the exception. Normality is relative, since the norm is a statistical average. As for the normativity of a human being, it rests in the capacity to create norms that are otherwise without a common measure among living creatures and are organized in a relationship of force that fully informs the individual human being. Health is the risk recognized and accepted by the individual to go beyond personal limits to open a perspective on new horizons, since the threat of death, which is the true antithesis of health, constitutes "the limitation from without, the negation of the living by the non-living" (Canguilhem 1962:31). Disability is a limitation from within the living, or rather "an order other than the most probable order" (p. 29).

By renewing the notions that inform the life sciences, Canguilhem made it possible to abandon the traditional categorizations of disabled people. His principal works are *La connaissance de la vie* (1965), *Le normal et le pathologique* (1966), and *Études d'histoire et de philosophie des sciences* (1970).

—Henri-Jacques Stiker

*See also* Normality; Normalization.

### Further Readings

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## ▣ CAPACITY BUILDING

*Capacity building* is a term used to describe the process by which individuals with disabilities and/or their organizations develop their ability to solve problems, address unmet needs, and maintain their well-being with less dependency on outsiders or professional help. The construct has special relevance to individuals with disabilities because of a long history of social biases and misperceptions about the "lack of capacity" of most people with disabilities to take charge of their own destinies, solve their own problems, and meet