

The Historical Origins of Stroke Rehabilitation

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Physical medicine and rehabilitation (PM&R) is a relatively young specialty that developed during the 20th century, with significant growth and development stimulated by two World Wars and by increasingly severe epidemics of paralytic poliomyelitis during the first half of the 20th century (1–4). During and after each of the World Wars, many soldiers returned with serious injuries and severe disabilities, and physicians and therapists were needed to treat and manage their chronic disabling conditions. This was particularly true after World War II, when the availability of antibiotics and improved surgical techniques allowed more injured soldiers to survive, albeit with significant disabilities. Similarly, over the same time period, increasingly severe epidemics of polio, frequent industrial accidents, and escalating motor vehicle accidents as a result of the increased availability of automobiles and higher-speed roadways added greatly to the burden of impairment and disability among the civilian population. Thus, events in the first half of the 20th century necessitated the development of new restorative treatment programs incorporating new physical and rehabilitative techniques, and the establishment of training programs for physicians and therapists to administer the treatments.

Nevertheless, with the exception of a relatively few scattered physical medicine physicians, it was not until the second half of the 20th century that specialists in rehabilitation medicine could profitably direct their energies exclusively, or even preferentially, to rehabilitation outside of the unprecedented and unsustainable circumstances of wartime military programs. Also largely missing until the second half of the 20th century were separate departments in academic and nonacademic medical centers devoted to the specialty, established training programs in PM&R, a sufficient number of PM&R practitioners, separate dedicated facilities for provision of rehabilitation services (e.g., dedicated wards in hospitals or separate rehabilitation centers), forums for the interchange of ideas (e.g., texts, journals, and professional societies), recognition by professional colleagues and the public that rehabilitation medicine specialists provided a needed service, and supportive legislation that would provide financial mechanisms to develop and provide such resources (5).

WORLD WAR I AND ITS AFTERMATH: BEGINNINGS OF PHYSICAL MEDICINE AND VOCATIONAL REHABILITATION

During much of the 19th century, physicians who employed physical modalities or advocated treatment with fresh air, water, exercise, and dietary modification were at risk of being labeled quacks by other members of the medical profession. However, near the turn of the century, orthopedic surgeons, in particular, began using selected physical treatments—massage, exercise, hydrotherapy—as part of special programs to augment medical care and convalescence within hospitals under physician supervision.

During World War I (1914–1918), physical and occupational therapy became increasingly important adjuncts to surgical practice, particularly in the treatment of orthopedic casualties, because surgeons realized that surgery alone was insufficient to achieve maximum return of function, and because empirical experience indicated that physical methods were useful adjuncts in the medical care and convalescence of wounded and disabled soldiers (1,4). In particular, with active U.S. involvement in the war beginning in 1917, Colonel Joel Ernst Goldthwait, MD (1866–1961), chief surgeon in the Orthopedic Medical Corp of the American Expeditionary Forces, and Colonel Elliott G. Brackett, MD, in the Home Service, also an orthopedic surgeon, enthusiastically supported a role for physical therapists in the rehabilitation of orthopedic casualties (6,7). Late in 1917, a program of Women's Auxiliary Medical Aides was established in the Surgeon General's Office, but by April 1918, this was transferred to the Division of Physical Reconstruction and renamed "Reconstruction Aides" (Figure 1.1) (6). Major (later Lieutenant Colonel) Frank B. Granger, MD (1875–1928), was named director of the Physiotherapy Service of the Reconstruction Division for the Army, and under his command the reconstruction aid program was directed by Chief Aide Marquerite Sanderson (formerly from Dr. Goldthwait's office in Boston) (6,8). Training programs for the reconstruction aides were established at Walter Reed General Hospital, headed by therapist Mary McMillan; later at Reed College in Portland, Oregon (where McMillan also initially taught during a leave of absence from Walter Reed); and eventually at 13 other programs across the country (6,9,10).



FIGURE 1.1 Reconstruction aides at work, U.S. Army Base Hospital No. 20, Chatel Guyon, France, during World War I.

Courtesy of the U.S. National Library of Medicine.

Colonel Frank C. Billings, MD (1854–1932), chief of the Division of Physical Reconstruction in the Medical Department of the U.S. Army, established separate sections for education, therapy, and clinical work (Figure 1.2). Military physicians in “reconstruction hospitals” then began treating wounded and disabled soldiers with occupational therapy (then called bedside occupations and curative workshops) and “physiotherapy” (a term indicating use of various physical methods in treatment, including heat, exercise, hydrotherapy, electrotherapy, and massage) (7). By the end of the war, therapy was provided by nearly 800 women volunteers (physical educators or nurses) trained as “reconstruction aides” under the Reconstruction Aide Program (4,6,7,10,11).

Some individuals criticized the prolonged bedside therapeutic activities provided by female reconstruction aides because they were felt to promote dependence and invalidism (12,13). However, in 1918, Billings described the work of the reconstruction aides and clearly distinguished it as superior to the types of “diversional” tasks previously employed:

[Ward work] has consisted frequently of work not so purposeful in its character, but rather as diversional in character, in the form of knitting, in the form of basket

weaving, etc. But the work which the Surgeon-General utilizes as curative in character in the general hospital for these soldiers is more purposeful than knitting, basket weaving and the like. In other words, it is of the kind and character of curative work that will look toward the training of the soldier for employment after his discharge from the Army. (14)

By the end of the war, physical reconstruction services were available in 35 general hospitals and 18 base hospitals across the country (4,15), and nearly 50,000 veterans (or about 40% of the 125,000 disabled during the war) had been treated at these facilities (16).

In 1923, Dr. F.B. Granger, who had been instrumental in developing the program for reconstruction aides in the United States and who was the first physician specializing in physical medicine to become a member of the American Medical Association (AMA) Council on Physical Therapy (9), summarized how physical therapy originated:

With the onset of the World War the urgent need of hastening the return of the wounded to the front lines, or rehabilitating them sufficiently so that they could be



FIGURE 1.2 Colonel Frank C. Billings (1854–1932), chief of the Division of Physical Reconstruction in the Medical Department of the U.S. Army during World War I. Knopf Collection.

Courtesy of the U.S. National Library of Medicine.

given noncombatant duty, thus presumably relieving an able-bodied man, forced the unification of [the separate treatment modalities]. The Surgeon General of the U.S. Army, at one stroke, completed their amalgamation when he defined physiotherapy as “Physical measures such as are employed under physiotherapy, including hydro, electro, mechano therapy, active exercises, indoor and outdoor games, and passive exercises in the form of massage.” Thus was born modern physiotherapy. (17)

Following the war, Dr. Elliott Brackett, a Harvard-trained orthopedic surgeon, promoted the establishment of hospitals “devoted to the medical care of all men who should be returned, also planned and equipped to reinstate the disabled soldier in the industrial world and allow him to become an independent wage earner” (16). Unfortunately, interest in rehabilitative services in the military waned after the war (1).

THE 1920s: BEGINNINGS OF PROFESSIONAL ORGANIZATIONS AND FORMAL TRAINING PROGRAMS

Physical Medicine

The 1920s and 1930s saw the beginnings of professional organizational development in the nascent field of PM&R. The so-called “physical therapy physicians” (i.e., physicians practicing early forms of physical medicine) began efforts to organize themselves and vied for a voice in the AMA. Specifically, in 1923, the American College of Radiology and Physiotherapy was founded as a professional organization of physicians who used physical methods to diagnose and treat illness and disability. Samuel B. Childs, MD, a radiologist from Denver, was elected as the first president. Very soon, however, radiologists separated and developed their own organizations so that, by 1925, the organization became the American Congress of Physical Therapy. Subsequent developments included the assimilation in 1933 of the American Physical Therapy Association (whose membership comprised only physicians) and various changes in the name of the organization initially intended to clarify the distinction between physicians and nonphysician therapists using physical methods in treatment (until the present name of the American Congress of Rehabilitation Medicine was selected in 1966).

Specialty physical medicine journals also developed during this period, corresponding to the increasing professional orientation of a small group of physicians to this new area of specialization. The journal *Radiology* began publication in 1920 under the editorship of Albert Franklin Tyler, MD (1881–?), and in 1926, it was renamed the *Archives of Physical Therapy, X-ray, Radium* to reflect its expanded focus. Subsequent name changes in the journal reflected an early shift away from radiology; a later distinction between physician and nonphysician therapists utilizing physical methods in treatment; and, ultimately, a broadening emphasis on rehabilitation (until the present name of the *Archives of Physical Medicine and Rehabilitation* was selected in 1952).

Most physicians who practiced physical medicine in this era used it as an adjunct to their regular general medical practices, but starting in the mid-1920s, some physicians began devoting their careers to this area and were recognized with academic faculty appointments. The first of these was John Stanley Coulter, MD, who joined the faculty of Northwestern University Medical School in Chicago in 1926 as the first full-time academic physician specializing in physical medicine. He initiated the first continuing teaching program in physical medicine in the form of 3- to 6-month, and later, 12-month courses. He became chairman of the AMA Council on Physical Therapy (18). For the next two decades, he was a key leader in the development of educational programs for the practice of physical medicine as well as in the development of professional organizations for physical medicine.

Physical Therapy

Formal training for allied health professionals in civilian practice was not available until 1918, when the Mayo Clinic initiated a training program in physiotherapy (19). In 1920, Lieutenant Colonel Hard D. Corbusier wrote to former reconstruction aide Mary McMillan, proposing the formation of a professional society of physical therapists to “advertise to all the physicians and surgeons of the country the importance of treatment by physical means and to elevate and standardize the work and place it on a more substantial basis” (6). In 1921, McMillan organized a group of nearly 300 former reconstruction aides to form the American Women’s Physical Therapeutic Association, which elected McMillan as the first president. The first issue of the association’s official publication, *The P.T. Review*, was published in March 1921, and the same year McMillan published *Massage and Therapeutic Exercise*, the first textbook written by a physical therapist (10,20). The organization was renamed the American Physiotherapy Association in 1922, and in 1930 the organization was incorporated to establish educational standards for physical therapists to support regulation of physical therapy practice and to cooperate with the medical profession to establish a central registry of physical therapists (10,21).

Occupational Therapy

In 1914, George Edward Barton—a disabled architect who had benefited from care he received at a convalescent hospital—introduced the term *occupational therapy* at a meeting of the Massachusetts State Board of Insanity in Boston (22) and subsequently founded Consolation House in Clifton Springs, New York, where he provided vocational assistance and workshop activities to other disabled people (13,22–24). In 1917, Barton organized the first meeting of the National Society for the Promotion of Occupational Therapy at Clifton Springs for “the advancement of occupation as a therapeutic measure, the study of the effects of occupation upon the human being, and the dissemination of scientific knowledge on this subject” (25). In addition to Barton, the founding members included Dr. William Rush Dunton, Jr., a Maryland psychiatrist, who was responsible for the occupations program at the Sheppard and Pratt Institute and had written monographs and articles on using occupational activities as therapy, including one of the first textbooks on occupational therapy, *Occupational Therapy—A Manual for Nurses* (1915) (26,27); Eleanor Clarke Slagle, who worked with Dunton at Johns Hopkins in Baltimore and who developed a regimented treatment program (“habit training”) for chronic schizophrenic patients; Susan Cox Johnson, director of occupations for the New York State Department of Public Charities; Thomas Kidner, an architect who was the vocational secretary of the Canadian Military Hospitals Commission; Isabel Newton, who was Barton’s secretary; and Susan Tracy, a nurse who was a training school superintendent and instructor of occupational therapy courses for nursing students, including the first such

course (in 1911) at the Massachusetts General Hospital Training School for Nurses (13,22–24,28,29). Barton became the first president (22). The organization was renamed the American Occupational Therapy Association in 1923 (22). The *Maryland Psychiatric Quarterly*, edited by Dunton, became the official organ of the National Society for the Promotion of Occupational Therapy until 1922, when the *Archives of Occupational Therapy* was first published as the official publication of the organization (13,22).

In 1929, Colonel James A. Mattison described the purposes of occupational therapy as employed at the National Home for Disabled Volunteer Soldiers:

One of the principal aims of occupational therapy is to create morale, and to provide every opportunity for the coordination of all hospital efforts toward returning the patient to community life and economic usefulness. (30)

The first textbook in the United States concerning occupational therapy, written primarily by occupational therapists, was *Principles of Occupational Therapy*, edited by Helen S. Willard and Clare S. Spackman and first published in 1947 (31).

Speech Therapy

Speech therapy had 18th- and 19th-century antecedents—particularly in the practical treatment approaches of the elocutionists (i.e., focused on improving speaking, orating, or singing); the beginnings of aphasiology with French neurologist Paul Broca (1824–1880), German neuropsychiatrist Carl Wernicke (1848–1905), and others; and the various “methods” for treating speech impediments, mispronunciation, and articulatory disturbances among the deaf (32,33). Development of professional organizations for speech therapy in the United States began with the founding of the American Speech and Hearing Association in 1925 as the American Academy of Speech Correction (33–35). In 1927, a nomenclature committee of the American Speech Correction Association outlined and described the conditions treated by “speech correctionists” under seven major categories: dysarthria, dyslalia, dyslogia, dysphasia, dysphemias, dysphonia, and dysrhythmia (33,36).

PROFILE OF FRANK KRUSEN (1898–1973): “THE FATHER OF PHYSICAL MEDICINE”

Frank Hammond Krusen (1898–1973) is widely regarded as “the father of physical medicine,” and during the 1930s and 1940s, was influential in the development of this field both in the United States and internationally (Figure 1.3) (37). Krusen graduated from Jefferson Medical College in Philadelphia in 1921, but his planned surgical career was interrupted when he developed pulmonary tuberculosis in 1924. During his convalescence at a sanitarium, he became interested in physical medicine. In particular, his own experiences and observations at this time helped Krusen



FIGURE 1.3 American physician Frank Krusen (1898–1973), “the Father of Physical Medicine.”

Courtesy of the U.S. National Library of Medicine with permission of the Mayo Clinic Archives.

realize that physical deconditioning increased dependence on institutional living and eroded self-esteem. He believed that self-assurance and independence could be restored in disabled patients with appropriate physical reconditioning, vocational rehabilitation, and reintegration into noninstitutional society (38). From this point forward, Krusen worked to develop physical medicine into a scientifically based and accepted medical specialty.

On his return to Philadelphia in 1926, Krusen was appointed as associate dean at Temple Medical School, where in 1929, he started the first academic department of physical medicine in the United States (38–40). In 1930, Krusen published an undergraduate curriculum in physical medicine (41). In 1935, at the invitation of one of the founders of the Mayo Clinic, surgeon William James Mayo, MD (1861–1939), Krusen moved to the Mayo Clinic in Rochester, Minnesota, where he founded the department of physical medicine (1935), initiated the first 3-year residency program in physical medicine (1936), and developed a school of physical therapy (1938) (18,19,39). In 1941, he was promoted to professor. In 1942, during World War II, he helped train a large cadre of medical officers from the U.S. Armed Forces

through 90-day intensive courses in physical medicine at the Mayo Graduate School of Medicine, with the trainees being labeled “90-day wonders” (3,15). Krusen’s influence was tremendous as judged by his own contributions as well as by the number and quality of his trainees, and their roles in, and subsequent contributions to, the further development of the specialty (42).

In addition to his role in the development of clinical practice and training programs in physical medicine, Krusen was an organizational leader for the specialty during the late 1930s and through the 1940s. In 1937, with William Bierman and John S. Coulter, Krusen established the American Registry of Physical Therapy Technicians to credential physical therapists (who were conferred the title of “registered physical therapist” on passing the certifying examination) (3,38). In 1938, with a small group of other pioneering physical medicine physicians, Krusen and Coulter founded the Society of Physical Therapy Physicians (later named the American Academy of Physical Medicine and Rehabilitation) “to develop physical therapy as a formally recognized specialty,” and Krusen was elected its first president (38). In 1941, Krusen wrote the first widely used textbook of physical medicine, *Physical Medicine: The Employment of Physical Agents for Diagnosis and Therapy* (43). Subsequently, Krusen played critical organizational roles in the founding and initial leadership of the Baruch Committee on Physical Medicine (1943), the American Board of Physical Medicine and Rehabilitation (1947), and the International Federation of Physical Medicine (1952).

In 1938, Krusen proposed the term “physiatrist” to designate the physician specializing in physical medicine, and further proposed that “physiatrist” should be pronounced with the accent on the third syllable (fiz ē at’ rist) to minimize confusion with “psychiatrist.” The name “physiatrist” was derived from the Greek words “physics” (physical phenomena) and “iatreia” (healer or physician) (15). Later, in 1946, the AMA Council on Physical Medicine voted to support the terms “physiatrist” and “physiatry” (11). In 1961, Arthur Watkins proposed “physiatrics” as a new name for the specialty of PM&R based on Krusen’s 1938 proposal, and Watkins further proposed changing the name of the American Academy of Physical Medicine and Rehabilitation to the American Academy of Physiatrics (44). However, Krusen supported maintaining the existing name of the organization because otherwise “the rest of the world wouldn’t recognize us” (44).

Beginning in the late 1930s, Krusen, in conjunction with more than a dozen other “physical therapy physicians,” repeatedly petitioned the American Medical Association for specialty status and an examining board for physical medicine, but controversies over certification, financing, and whether PM&R should be an independent specialty or a subspecialty delayed its successful resolution for more than a decade. Ultimately, under Krusen’s leadership, the American Board of Physical Medicine and Rehabilitation was founded in 1947 and Krusen served as its first chairman (from 1947 to 1951) (39,40).

From 1943 to 1951, Krusen served as a critical leader of the Baruch Committee on Physical Medicine (later the Baruch Committee on PM&R), an activity that greatly fostered the development of physical medicine in the United States (3,18,39,45). The Baruch Committee was established by financier and philanthropist Bernard Mannes Baruch (1870–1965) in honor of his father, Simon Baruch, MD (1840–1921), to advance physical medicine through education, clinical care, and research (Figure 1.4). Dr. Ray Lyman Wilbur (1875–1949), who had been the third President of Stanford University, was the initial chairman of the Committee and Krusen served with him on the Administrative Board; Krusen was also selected as the chairman of both the Scientific Advisory Committee and the Committee on Physical Rehabilitation (3). The Baruch Committee soon recommended the establishment of teaching and research centers for physical medicine, fellowships and residencies in PM&R, the promotion of teaching and research in PM&R in medical schools,



FIGURE 1.4 American financier and philanthropist Bernard Mannes Baruch (1870–1965) shown in 1913, as chairman of the War Industries Board. Photograph by Harris & Ewing.

Courtesy of the Library of Congress Prints and Photographs Division, Washington, DC.

and the development of the American Board of Physical Medicine and Rehabilitation (3,46). Through the remainder of the 1940s until its disbanding in 1951, the Committee provided grant funds for fellowships, and for teaching and research programs in physical medicine at universities and medical schools. The legacy of the Baruch Committee included a marked increase in the number of medical schools teaching PM&R, a distinct increase in the number of residencies in PM&R, and more than 30 Baruch Fellows who went on to become department heads in medical schools, the military, or Veterans Administration hospitals (3).

POLIO EPIDEMICS EXPANDED THE NEED AND ROLE FOR PM&R AMONG CIVILIANS

Although unrecognized at the time, the growing epidemics of paralytic poliomyelitis beginning in the 1890s and occurring throughout the first half of the 20th century were partly an unanticipated consequence of improved sanitation. Hygienic advances delayed exposure to polioviruses from early infancy (when protection against paralytic disease was afforded by maternal antibodies) to later in childhood or adulthood, at which time paralytic manifestations were much more likely, a phenomenon expressed memorably by pediatrician John F. Modlin, MD: “Polio . . . was the unanticipated consequence of the invention of the flush toilet and the adoption of the use of toilet paper” (47).

The first major epidemic of poliomyelitis in the United States, and the one that brought polio into national consciousness, occurred in 1916: Nationwide, there were 27,000 cases, with 6,000 deaths, almost all under 5 years of age; and a large number of the survivors were left with lifelong disabilities and, often, deformities. Although there was considerable variability from year to year, subsequent annual summer epidemics were less severe, until they began progressively increasing during the 1940s and early 1950s, with the worst epidemic in 1952 causing nearly 58,000 cases of paralytic poliomyelitis. As increasing numbers of older children and adults became affected during the 1930s and afterward, the original label of “infantile paralysis” was replaced by either the medical term “poliomyelitis” or the shorter term “polio.” Because mortality was high, and because survivors were often left with severe paralysis and resulting disability, these epidemics caused widespread anxiety and fear, particularly during the summer months (48). These polio epidemics also led to major advances in respiratory management and physical therapy (49–51), and further established the role of physiatrists in the management of neuromuscular diseases, especially limb and respiratory muscle weakness, contractures, and gait disorders.

The “Iron Lung”

In 1928, following the early epidemics of poliomyelitis in the United States, industrial hygienist Philip A. Drinker (1894–1972) and physiologist Louis Agassiz Shaw, Jr. (1886–1940) at Harvard University designed an electrically



FIGURE 1.5 A U.S. Army nurse and two corpsmen attending a poliomyelitis patient in an iron lung, 1949.

Courtesy of the U.S. National Library of Medicine.

powered tank respirator to facilitate the breathing of patients paralyzed by poliomyelitis (Figure 1.5) (52). This “iron lung” was the first practical means of respiratory support, and in 1929, Drinker and pediatrician Charles F. McKhann soon demonstrated the potential of artificial respiration, using the iron lung for an 8-year-old girl with poliomyelitis who had developed respiratory failure and coma (53,54). Manufacture of these “iron lungs” began in the early 1930s and expanded in the 1940s and early 1950s, until the respirators were replaced in the late 1950s and early 1960s by more sophisticated ventilation devices. The iron lung required intensive nursing care and respiratory therapy, and a supporting hospital infrastructure. Although the iron lung saved thousands of lives, many patients, who would otherwise have died, survived with severe disabilities requiring considerable physical therapy, orthotics, and adaptive equipment.

“Sister” Kenny: An Outspoken Nurse Challenges the Orthodox Treatment of Polio

From the 1920s through at least the early 1940s, the orthodox treatment for polio consisted largely in absolute immobilization of affected limbs through splinting or the use of plaster casts (often for many months) and, subsequently, orthopedic braces (often permanent), leading to disuse atrophy, joint contractures, and lifelong disability (10,55–57). However, since 1911, an unregistered independent nurse practitioner named Elizabeth Kenny (1880–1952) had been treating patients with poliomyelitis using an alternative approach she had developed empirically in a sparsely populated backcountry area of Australia in ignorance of the prevailing orthodox treatments (58–60). Later, when she came into prominence, Kenny employed the title of “Sister,” an honorific designation for a head nurse in the British system that she

earned during her military service in the Australian Army Nurse Corps during World War I (60–62). “Sister” Kenny’s approach to the treatment of poliomyelitis used physical methods (e.g., the labor-intensive application of moist warm wraps of heavy woollen cloth for muscle spasms, aggressive use of passive range of motion, and massage), avoidance of immobilization and bracing, and strong encouragement of functional independence, as well as early mobilization and prompt return to normal activities, coupled with confident optimism for improvement (58,59,61,63–65). Kenny later criticized the immobilization approach then in vogue, claiming that it prolonged muscle spasms, promoted joint stiffness, and prevented restoration of normal muscle action:

My reasons for the condemnation of the principles of immobilization as generally accepted are as follows:

1. Immobilization prevents the treatment of the disease, that is, the symptoms of the disease, in the acute stage.
2. It prolongs the condition of muscle spasm and prevents its treatment.
3. It prevents the treatment for the restoration of coordination of muscle action, a serious error.
4. It promotes the condition of stiffness which according to all reports prevents satisfactory treatment for the symptoms that brought about the condition (muscle spasm) or the development of muscle power by reeducation, or re-awakening of impulse. (64)

During the 1930s, 10 Sister Kenny Clinics were established in eastern Australia, initially as “Muscle Re-Education Centres” (58). However, Kenny was not accepted by orthodox medicine in Australia, was denounced by an Australian Royal Commission in the late 1930s, and was widely criticized by orthopedic surgeons and other physicians, who charged that she understood neither the pathophysiology of the disease nor the physiology of muscle (58,59). Nevertheless, her approach was empirically successful and she developed a large popular following. In 1939, the Queensland government—in spite of the unpopular conclusions of its own Royal Commission—ordered that the Kenny treatment be made available in the Queensland public hospital system (58,59).

Kenny came to the United States in 1940, where her ideas were initially ignored or resisted until tested by Dr. Wallace Cole, chief of orthopedic surgery at the University of Minnesota Medical School and Dr. Miland Knapp, a surgeon who chaired the school’s department of physical therapy (66). The Kenny methods were eventually found to reduce length of hospital stay, greatly diminish contracture formation, and improve functional recovery (66–69). As a result, with encouragement from the American Medical Association and initial funding from the National Foundation for Infantile Paralysis and other donors, a well-regarded and very successful Sister Kenny Institute (later known as the Sister Kenny Rehabilitation Institute) was established in Minneapolis in early 1942 and developed a strong affiliation with the University of Minnesota Medical School, with rotating residents and various specialist staff including physiatrists, orthopedic surgeons, neurologists,



FIGURE 1.6 “Sister” Elizabeth Kenny (1880–1952), shown here demonstrating therapy techniques at the Sister Kenny Institute in Minneapolis, Minnesota, c. 1942.

Courtesy of the Minnesota Historical Society, St. Paul, Minnesota.

and others (Figure 1.6) (10,50,58,60,62). The Kenny methods were widely adopted in the United States and elsewhere in the 1940s (though not in Australia), and were taught to physical therapists and physicians at training satellites around the country. Although the controversial Kenny had her detractors, she also had numerous supporters, including Krusen of the Mayo Clinic. Kenny’s approach represented a significant advance in the care of paralyzed patients and helped foster the growth of physical therapy and physical medicine (6,50,70).

In retrospect there is no denying that Sister Kenny’s ideas and techniques marked a turning point, even an about-face, in the aftercare of paralytic poliomyelitis. By determination and sheer willpower she helped to raise the treatment of paralyzed patients out of the slough into which it had sunk in the 1930s. The system which prevailed before her advent, that is, prolonged immobilization of affected limbs which in some instances led to a certain amount of calculated neglect, militated against involving the patient in early efforts to aid return of muscle function. It also eliminated the element of continued encouragement, which [is] so important as a psychological asset to rehabilitation. There was little use in exhorting a patient to exert himself physically if he was in a plaster cast. (71)

FDR, the National Foundation for Infantile Paralysis, and the March of Dimes

Franklin Delano Roosevelt (1882–1945), the most famous victim of polio, contracted the disease in the summer of 1921 and was permanently paralyzed from the waist down (57).

Despite his disability, Roosevelt was later elected to the first of four terms as President of the United States in 1932 (57). From the time he became disabled, Roosevelt played an important role in the development of rehabilitation medicine, helped remove some of the social stigma from physical disability, provided inspiration and hope, promoted the idea that polio victims could become “normal” again (even if this was partly because of careful media management limiting the public’s knowledge of the extent of his disability), and provided a mechanism for widespread supportive social action and philanthropy. In 1926, Roosevelt purchased a spa in Warm Springs, Georgia, to help facilitate his personal rehabilitation. By 1927, Roosevelt had founded the Georgia Warm Springs Foundation, which helped develop physical therapy and rehabilitation approaches for polio victims (50). In 1937, the Foundation was reorganized as the National Foundation for Infantile Paralysis (and officially incorporated in 1938), under the direction of Roosevelt’s former law partner, D. Basil O’Connor (1892–1972). Under O’Connor’s effective organizational leadership, the National Foundation began an unprecedented, innovative, and highly successful fundraising campaign utilizing an annual “President’s Birthday Ball” with President Roosevelt and a variety of celebrities promoting the event and print advertisements with images of happy children (“poster children”) in wheelchairs or braces and crutches asking for financial support, as well as public appeals requesting people to send dimes directly to the White House to help find a cure for polio; this latter campaign was labeled the “The March of Dimes” by entertainer Eddie Cantor (1892–1964) as a play on the words of “The March of Time” newsreel series (72–76). The first March of Dimes appeal in 1938—during the severe 1937 to 1938 recession following closely on the heels of the Great Depression of 1929 to 1934—generated extraordinary interest and raised an unprecedented \$268,000 (the equivalent of over \$3.4 million in year 2007 currency) (Figure 1.7) (76–78). A stunned President Roosevelt commented on the eve of his birthday:

During the past few days bags of mail have been coming, literally by the truck load, to the White House. Yesterday between forty and fifty thousand letters came to the mail room of the White House. Today an even greater number—how many I cannot tell you, for we can only estimate the actual count by counting the mail bags. In all the envelopes are dimes and quarters and even dollar bills—gifts from grownups and children—mostly from children who want to help other children to get well. Literally, by the countless thousands, they are pouring in, and I have figured that if the White House Staff and I were to work on nothing else for two or three months to come we could not possibly thank the donors. Therefore . . . I must take this opportunity . . . to thank all who have aided and cooperated in the splendid work we are doing. (76)

The public’s fear of contracting the disease, appeals to altruism with heartbreaking stories of afflicted children, requests



FIGURE 1.7 President Franklin Delano Roosevelt (1882–1945) and his former law partner Basil O’Connor (1892–1972) shown counting dimes at the White House, c. 1938.

Courtesy of the March of Dimes.

from admired role models (movie stars and politicians), and hope that the disease would soon be conquered were all used so effectively in the campaigns that the nonprofit National Foundation became the largest private charity in history. The National Foundation led the “first large-scale, nationwide biomedical initiative” by a charitable organization (75) and, as a result, was instrumental in subsidizing the hospital and rehabilitation costs of polio patients, funding basic and applied research concerning the causes and prevention of polio in the 1940s and early 1950s, training nurses and physical therapists in rehabilitation, sponsoring pilot programs to improve the teaching of rehabilitation medicine in medical schools in the early 1950s, and, ultimately, underwriting the Salk Vaccine Field Trial in 1954 (6,72,73,75). The National Foundation officially changed its name to the March of Dimes in 1979 (after the threat of polio in the United States had passed) (75).

The Salk Vaccine Field Trial of 1954 and Aftermath

Austrian biologist and physician Karl Landsteiner (1868–1943) and his assistant Erwin Popper demonstrated as early as 1908 that poliomyelitis was transmitted by a virus, work for which Landsteiner won the 1930 Nobel Prize in Physiology or Medicine (70,79,80). By 1948, neuroscientist David Bodian, MD, PhD (1910–1992) and colleagues at Johns Hopkins University, and virologist John Rodman Paul, MD (1893–1971) and epidemiologist James Dowling Trask, MD, PhD (1890–1942) at Yale University independently showed that there were three strains of poliovirus (rather than one) as defined by cross-protection within the same group—a finding confirmed by the more extensive work of the Committee on Typing of the National Foundation for Infantile



FIGURE 1.8 American virologist Jonas Salk (1914–1995). Salk developed a killed-virus polio vaccine.

Photograph taken by Yousuf Karsh (1908–2002) for *Wisdom Magazine* (Cover photograph August 1956, Vol. 1, No. 8). (Public domain photograph courtesy of Wikimedia Commons).

Paralysis in 1951 (in which Jonas Salk was a participant) (70,80–85). In 1949, microbiologist John Franklin Enders, PhD (1897–1985), along with virologist Thomas Huckle Weller, MD (1915–2008) and microbiologist and pediatrician Frederick Chapman Robbins, MD (1916–2003), working at Harvard Medical School and Children’s Medical Center in Boston, first cultivated the poliovirus in (nonnervous) tissue culture, for which they were later awarded the 1954 Nobel Prize in Physiology or Medicine (86–90). Also by 1954, several researchers, including epidemiologist, virologist, and pediatrician Dorothy Millicent Horstman, MD (1911–2001) at Yale, had demonstrated that there was a period of viremia preceding neurologic involvement (91,92). These important advances made possible the development, by virologist Jonas Edward Salk, MD (1914–1995), of an inactivated trivalent poliovirus vaccine, which was tested in 1954 in a huge clinical trial funded by the National Foundation for Infantile Paralysis (Figure 1.8) (74,93–96). The 1954 Field Trial of the Salk vaccine was the largest public health experiment ever, involving 1.8 million children who were labeled “Polio Pioneers” and were inoculated with either vaccine or placebo, or were simply observed (70,72,93,97,98). On April 12, 1955, at a press conference in Ann Arbor, Michigan, epidemiologist and virologist Thomas Francis Jr., MD (1900–1969), who had conducted the field trial, declared that the Salk inactivated polio vaccine was both safe and effective (93,98,99). That same afternoon, an advisory committee to the Laboratory of Biologics Control, the federal agency that was responsible for licensing biologic products, recommended that vaccine licenses be granted to five pharmaceutical companies: Eli Lilly, Parke-Davis, Wyeth, Pitman-Moore, and Cutter Laboratories.



FIGURE 1.9 Russian-American virologist Albert Sabin (1908–1993). Sabin developed a live attenuated-virus polio vaccine. From Theodore Woodward’s *The Armed Forces Epidemiological Board: Its First Fifty Years* (1990).

This image is a work of a U.S. Army soldier or employee, taken or made as part of that person’s official duties. As a work of the U.S. federal government, the image is in the public domain.

However, shortly thereafter, unforeseen manufacturing difficulties with clumping of material and inadequate formaldehyde inactivation of the virus during large-scale processing resulted in a huge outbreak of iatrogenic paralytic poliomyelitis (the so-called “Cutter Incident”) with muscle weakness developing in 70,000 people, of whom 164 developed severe paralysis and 10 died (100–104). The litigation that followed (particularly *Gottsdanker v. Cutter Laboratories*, 1957) led to new legal interpretations (i.e., the doctrine of liability without fault) and, ultimately, the development of the National Vaccine Injury Compensation Program in 1986 (103,104). Although these legal issues dragged on for decades, the manufacturing problems were soon corrected, and with wide-scale immunization using the Salk vaccine, the rates of paralytic poliomyelitis plummeted.

In 1957, Russian-American virologist Albert Sabin, MD (1908–1993), utilizing the time-consuming process of infecting

monkeys with poliovirus, developed a trivalent live attenuated polio vaccine that was then tested in Russia, endorsed by the American Medical Association in 1961 even before American field trials were begun, and, ultimately, licensed in the United States in 1963 (Figure 1.9). The Sabin vaccine soon became the polio vaccine of choice, because it (a) was less costly, (b) required minimal training to administer, (c) prevented the disease carrier state, and (d) helped prevent the spread of wild poliovirus. However, by this time, the rates of polio in the United States had dropped to 50 to 100 cases per year—down from tens of thousands per year—so the Sabin vaccine had a relatively limited impact on overall polio incidence in the United States, but it did have an important role around the world. By the early 1970s, the remaining incident cases of paralytic poliomyelitis in the United States were almost exclusively either imported cases or those caused by the vaccine itself. The Sabin oral polio vaccine was discontinued in the United States in 2000, because the continued risk of vaccine-related polio outweighed the potential benefits of a live-virus vaccine.

PROFILE OF HOWARD RUSK (1901–1989): THE FATHER OF COMPREHENSIVE REHABILITATION MEDICINE

Origins of Comprehensive Rehabilitation During World War II

In 1942, internist Howard Rusk, MD (1901–1989) (Figure 1.10) left his well-established medical practice in St. Louis to join the Army Air Corps. As Chief of Medical Services at the 1,000-bed hospital at Jefferson Barracks in St. Louis, Rusk observed both a high degree of boredom among the patients and a high rate of readmission because patients were not physically fit enough to return to active duty in their units after hospital discharge, even though they were no longer in need of acute hospitalization (148,105–107). Rusk, therefore, sought to engage the patients in mental and physical restorative and training activities that would utilize their time efficiently, increase their fitness, and decrease the rate of recidivism. Rusk’s approach to rehabilitation emphasized treating the entire person, including his or her emotional, psychological, and social needs, and not just the illness or a specific disability. By 1943, seven special “convalescent hospitals” had been established in the Army Air Corps, with multidisciplinary staff comprising

medical and surgical specialists, but also physical therapists, educators, athletic trainers [later called “corrective therapists” and still later called “kinesiotherapists”], occupational therapists, social service workers, personal counselors, and vocational guidance advisors—all of whom worked as a team to meet on an individual basis, the needs of the “whole man.” . . . [A] broad program of rehabilitation was put into operation at each convalescent hospital, with the result that each hospital became part school, gymnasium, machine shop, psychiatric clinic, vocational guidance center, and town hall. (45)



FIGURE 1.10 Dr. Howard A. Rusk (1901–1989), the father of comprehensive rehabilitation medicine.

Courtesy of the National Library of Medicine.

Rusk's efforts were soon recognized by generals (Dr.) David N.W. Grant (1891–1964) and Henry Harley (Hap) Arnold (1886–1950), whereupon Rusk was sent to Washington, DC, in 1943 to set up similar programs for all 253 Army Air Corps hospitals (1,105,108). Rusk's novel Convalescent Training Program was highly effective in decreasing hospital readmissions, saving man-hours, and giving injured and disabled soldiers hope and purpose (Figure 1.11).

Despite such success, many of us felt our program was grossly inadequate. The feeling became intensified when wounded boys from the battlefields began being packed into our hospitals by the planeload. Suddenly we were faced by men with broken bodies and, all too often, broken spirits. We concluded that our program was a school-boy project in the context of what needed to be done for the severely wounded—the amputees (the double, triple, and quadruple amputees), the paraplegics and quadriplegics, the blind, the deaf, the disfigured, the emotionally disturbed. These men would need complete rehabilitation, whatever that might be—I wasn't sure. Just exactly what could be done for them? . . . It was horrible to realize that there was no precedent for rehabilitation programs on a large scale in the military. And as far as I knew, there was no extensive civilian programs either. (105)

Later, similar programs, loosely modeled after Rusk's Convalescent Training Program, were adopted by all branches of the service at the instigation of Bernard Baruch and the subsequent request of President Franklin Delano Roosevelt (1882–1945) to Secretary of War Henry Lewis Stimson (1867–1950) (1). Rusk had sought Baruch's assistance, and the letter drafted by Baruch for the President's signature became *de facto* military policy giving official standing to rehabilitation medicine:

My dear Mr. Secretary, I'm deeply concerned about our casualties returning from overseas, as I know you are. I would like you to see that no one is discharged from service until he has had the full benefit of hospitalization, which will include not only medical care but resocialization, psychological adjustment and rehabilitation. I would like you to see that this is put in operation as soon as possible. (105)

Because of the limited rehabilitation programs available prior to World War II, and the widely held expectation at the time that disabled people could not be productive, people with strokes or other brain and spinal cord injuries received, at best, custodial care and often died within a short time (1).

I recall someone asking me how paraplegics had lived up to that time. The answer was, except in extremely rare cases, they usually died—their life expectancy in those days was often less than a year. They got terrible bedsores, developed kidney and bladder problems, and simply lay in bed, waiting for death. It was almost the same with strokes. The old wives' tale was that you had one stroke, and then you sat around waiting for a second one, or a third one, or however many it took to kill you. If you had any kind of brain injury affecting your locomotive functions, everyone assumed your life was finished. (105)

Rusk's experience in the rehabilitation of wounded soldiers during World War II helped usher in the concept of comprehensive rehabilitation, with both utilitarian and humanitarian aims (1).

The modern concept of "the treatment of the whole man" [developed by Rusk, himself] did not develop . . . until World War II, when rehabilitation got its biggest impetus because so many wounded survived—but survived with severe disabilities. (46)

One of our most immediate frustrations in early 1943 was that if we discharged these wounded and disabled veterans from the service—which we had to do since they could no longer function as soldiers—we were turning them over to the Veterans Administration, which at that time was like sending them into limbo. The V.A. had no program for them. They would simply lie around getting custodial care, with nothing to do, bored to distraction, helpless, hopeless, waiting for some kind of infection or disease



FIGURE 1.11 Vocational rehabilitation posters of the U.S. Army Air Forces during World War II. Photomechanical print created by Jack Wittrup (1912–1987). Published by the Training Aids Division, 1944.

Courtesy of the U.S. National Library of Medicine.

to carry them off. Gradually the concept of rehabilitation came to me as I found out how much really could be done for these men. In the beginning, I knew only that everything possible should be done to return them to physical and mental health. This meant finding ways for them to function despite their disabilities. First, I had to remember that this was the Air Force, that we were fighting a desperate war, and that we needed all the manpower we could find. It was immediately important, then, to make these men in some way able again. Our initial aim had to be to send them back to duty in the best possible condition and in the shortest time. If they could no longer do their previous jobs, we should help them choose jobs they could do, and then retrain them. This approach would be beneficial to the Air Force and it seemed the best for the boys themselves, too. (105)

The development of comprehensive rehabilitation in the military during World War II was truly novel and the outcomes were unprecedented (1):

We discovered we had saved at least forty million man-hours of duty time, and that we had gotten more sick or injured men back on duty than any branch of service had done during any war in history. More important, we had prepared thousands of boys for useful roles in

civilian life after the war who might otherwise have wasted away for years in veterans hospitals. And by proving the value of rehabilitation, we had made certain that the Veterans Administration, after this war, would actually rehabilitate its disabled men rather than letting them languish in bed, or die for lack of understanding and a program. It is worth noting that of the four hundred men who became paraplegics in World War I, a third died in France, another third died within six weeks thereafter, and of the remaining third, 90 percent were dead within a year. In World War II there were 2,500 American service-connected combat paraplegics, and three-fourths of them were alive 20 years later. I might add parenthetically that of these survivors, 1,400 were holding down jobs. (105)

Rusk earned a Distinguished Service Medal for his work in the U.S. military, and retired as a Brigadier General in the U.S. Air Force Reserve.

Later, in retrospect, he was struck by the irony of such progress having been made in the field of rehabilitation medicine as a result of a brutal war:

It is paradoxical that through war, a concerted effort to annihilate man, we have learned more and better ways to preserve him. (45)

Change in Management of Disability After Stroke

As an internist prior to World War II, Rusk had been frustrated with the options available for treating patients disabled by stroke, and had felt that his own knowledge was woefully inadequate. Rethinking his prior management and discussing his career options with several former patients who had suffered from stroke reinforced Rusk's belief in the concept of comprehensive rehabilitation and gave him the determination to abandon his previous internal medicine practice and seek opportunities to develop this concept for civilian patients.

There was so little you could do to help a stroke victim in those days that, like many other doctors, I had developed a technique in dealing with them that did no more than pacify them. I had scores of them in my practice, people who were partially paralyzed, and who, therefore, sat home all day, no longer considered fit to work, and with nothing to do but think about their condition. They would want to see me periodically for checkups, but I wanted to see them as seldom as possible. I didn't realize it at the time, but in front of such patients I was overcome by a feeling of insecurity. Deep down inside I felt guilty because I didn't know how to help them. Whenever they came into the office they wanted to talk. They would talk for an hour if you let them, while thirty other people sat in the waiting room. So I would go through the routine of taking their blood pressure . . . and prescribe a little meaningless change in their medication that would make them feel that at least something was being done. Then I'd hurry out of the room while the nurse came in to dismiss them. I didn't want to talk to them because I really didn't know what to say, and I'm sure that's always been true of most doctors everywhere . . . If [a patient] was paralyzed . . . or disabled in some other way, there was virtually no one to whom you could send him. You could get him maybe a "nickel's worth" of physical therapy, and that was about all. Such reminiscences reinforced my determination to throw my energies into rehabilitation. (105)

Moreover, by this time Rusk had an entirely different view of the potential for rehabilitation of patients following a stroke, emphasizing what could be done, focusing on remaining abilities, and utilizing simple techniques and equipment to minimize contractures and other secondary impairments and to maximize function:

There are a number of simple progressive procedures in the rehabilitation of the hemiplegic who suffers from one of the commonest disabilities seen in general practice. In the early stages of treatment, the following procedures should be instituted to prevent deformities: (1) footboard or posterior leg splint to prevent foot drop; (2) sandbags to prevent outward rotation of the affected

leg; (3) a pillow in the axilla to prevent adduction of the shoulder, and (4) quadriceps setting to maintain muscle strength. All of these procedures are relatively simple and require no special equipment. Their use, however, will prevent crippling anatomic deformities and hasten the rehabilitation of the patient.

The next procedure indicated is the institution of pulley therapy. This can be done simply with a small pulley attached to a goose neck pipe over the head of the bed, the ordinary clothes line rope being used with a 1 inch (2.5 cm) webbing for the hand loop. With the stretching and passive exercise provided by pulley therapy, the range of motion can be increased and adhesions prevented. Pulley therapy has the advantage over the usual stretching exercises that are done passively, for the patient, knowing his own pain threshold, will proceed to fully tolerated motion much more quickly. . . .

[Ambulation] should be started by (1) the practice of balance in the standing position, progressing to parallel bars; (2) the teaching of a heel and toe gait to minimize clonus and to reestablish normal walking habits stressing reciprocal motion, and (3) a short leg brace, which will be needed in approximately half of all cases to correct foot drop. All of the equipment for training in ambulation is simple and readily obtained by the general practitioner. If parallel bars are not available, two kitchen chairs may be substituted. In the advanced stages of retraining, ambulation is continued with (1) instruction in crutch walking, starting usually with the alternate four point gait, and (2) teaching elevation, stressing climbing steps, curbs, stairs and ramps. Concurrently with the training in ambulation, attention should be given to retraining in the activities of self care and daily living . . . With such a program, many of the complications usually following apoplexy can be avoided and a great deal of time and ability salvaged. (109)

Not only did Rusk feel that such approaches were extremely helpful, but he also felt strongly that *failure* to provide rehabilitation to patients was a form of medical negligence:

The physician who fails to see that those patients under his care receive the full benefits of modern methods of medical rehabilitation and retraining is in the same category as the physician who still persists in using dietary restriction alone in the management of diabetes, when insulin is available, for medical care is not complete until the patient has been trained to live and work with what he has left. (109)

Rusk later explained the potential for rehabilitation of stroke patients to colleagues at a meeting of the American College of Physicians in Boston:

I'm talking about the two million people in this country who have suffered strokes and are now sitting around,

waiting to die because no one is helping them to live. I'd like to tell you today about a few simple things you can do for many of these people, right in your offices, or in the home or bedside. I told them how to prevent painful hips by sandbagging the patient's leg. I told them how to sandbag a shoulder so it wouldn't become what we call "frozen" and require several weeks of painful therapy and stretching to get it back to normal. I took out some props and showed them how they could make an exercise device for arms and shoulders for stroke victims simply by using a window pulley and six or eight feet of clothesline. I pointed out that a patient could help himself more with this device than a therapist could help him because, by doing it himself, he could sense the pain threshold and therefore stretch farther than a therapist would dare to try. I talked about aphasia, the speech difficulty stroke victims suffer, which seems to me one of the most frustrating problems of all. It's like not being able to say an old friend's name, multiplied to infinity. As I talked, this time I noticed there was absolute silence in the hall, and instead of seeing people leave, I noticed that more people kept arriving until, by the end of my presentation, they were standing in the aisles. (105)

Although such information generated considerable interest, referral options were extremely limited because of the lack of comprehensive rehabilitation programs across the country.

Program for Civilian Rehabilitation

After World War II, Rusk began efforts to establish a program for civilian rehabilitation, based in large part upon what he had learned in the military (1). He initially intended to open a rehabilitation institute in St. Louis, where he had practiced internal medicine for 16 years prior to his military service, but colleagues there were not supportive.

I can't say the idea was well received. The orthopedists, in particular, said, "We're doing all that anyway," and it was true that they had adopted some good methods of therapy. But they failed to see my point: the whole person needed rehabilitation, not just the part of him that had been damaged. They had no concept of the emotional problems which follow disability, or the problems of job placement, or the other fundamentals behind our philosophy. (105)

In 1945, Rusk joined the staff at New York University Medical School, and several wards in Bellevue and Goldwater Hospitals were designated for rehabilitation, although initially the beds were also simultaneously utilized by other services. The previously separate programs for physical and occupational therapy were combined into



FIGURE 1.12 American physician and rehabilitation medicine pioneer George Gilbert Deaver (1890–?).

Courtesy of the U.S. National Library of Medicine with permission of the New York University Archives.

a new Department of Rehabilitation Medicine (3), and Rusk hired George Gilbert Deaver, MD (1890–?), from New York's Institute of Crippled and Disabled as the medical director (Figure 1.12) (3,46). Deaver had been a pioneer in rehabilitating the severely handicapped, including those with spinal cord injury, cerebral palsy, muscular dystrophy, multiple sclerosis, and rheumatoid arthritis. "At a time when these patients were being rejected and discarded as permanently disabled, Deaver was accepting of them and patiently working with them to achieve the best possible outcomes through rehabilitation" (3). Deaver made unprecedented progress in rehabilitating those with spinal cord injury to independence in self-care, crutch or brace-assisted ambulation, or wheelchair living (3,46): According to Rusk, "It was he who first taught paraplegics how to walk" (46). Deaver had also developed tools and techniques for assessing activities of daily

living (as a guide for independent living capability), crutch walking, and prevocational evaluation (3,46). By 1947, Rusk and Deaver had established the “first comprehensive, total medical rehabilitation program in any community hospital” in the United States at Bellevue Hospital in New York (109).

Despite Rusk’s enthusiasm and his previous successes, his initial civilian efforts were regarded skeptically by colleagues:

Many people, even in the medical profession, considered it foolish to spend money or effort on such a “frilly boondoggle.” It wasn’t that they disapproved of getting disabled people onto their feet and back into the mainstream of life; it was just that they didn’t think it was possible. (105)

Nevertheless, Rusk persevered and gained the support of prominent philanthropists, including Bernard Baruch, Polish-American builder and developer Louis J. Horowitz (1875–1956) and his wife Mary Decker Horowitz (c. 1877–c. 1966), and retail innovator Bernard Feustman Gimbel (1885–1966) and his wife Alva Bernheimer Gimbel (1893–1983). In 1950, Rusk founded the Institute of Physical Medicine and Rehabilitation at New York University Medical Center. The institute opened its doors in 1951, but was initially derided as “Rusk’s Folly” by former colleagues in St. Louis (108). Renamed the Howard A. Rusk Institute of Rehabilitation Medicine in 1984, 2 years after Rusk’s retirement in 1982, the institute is now the largest university-affiliated center for treatment of civilians with disabilities and for research and training in rehabilitation medicine (110).

Promoting Rehabilitation Medicine

Rusk worked tirelessly, promoting the nascent field of rehabilitation and increasing public awareness of the need for rehabilitation in the spectrum of medical practice in numerous speeches and consultations across the country and around the world, in a weekly column on health issues for *The New York Times* (which Rusk continued until 1971), through influential private sector and government contacts, and through the establishment of rehabilitation training programs, which helped expand the message through various disciples (1). In 1955, Rusk founded the World Rehabilitation Fund to provide technical assistance for the development of rehabilitation programs in underdeveloped countries, as well as funding for education and training programs on prosthetics around the world, and grants for foreign physicians to study rehabilitation in the United States: “Its basic aim was to sponsor international projects which would help the handicapped and create a better understanding of them and their problems” (105). Rusk also authored several books, including *New Hope for the Handicapped* (1949) and *Living with a Disability* (1953), both with his colleague Eugene (Jack) Taylor (1913–1978); served as the senior author of *Rehabilitation Medicine* (1958);

and wrote his acclaimed autobiography, *A World to Care For* (1972), which summarized the development of his concepts of comprehensive rehabilitation.

In his autobiography, Rusk explained why he got such satisfaction from working with disabled people:

You don’t get fine china by putting clay in the sun. You have to put the clay through the white heat of the kiln if you want to make porcelain. Heat breaks some pieces. Life breaks some people. Disability breaks some people. But once the clay goes through the white-hot fire and comes out whole, it can never be clay again; once a person overcomes a disability through his own courage, determination and hard work, he has a depth of spirit you and I know little about . . . Rehabilitation is one branch of medicine in which the patient has more power than the doctor in setting the limits and possibilities. The doctor can tell the patient what to do, but only the patient himself can decide how much he’s going to do. In making these decisions, patients are constantly teaching us doctors new things about rehabilitation by proving that they can do more than we had presumed possible. (105)

Rusk promoted these ideas among medical students as well:

When I lecture to medical students, it’s the brightest day of the year for me. They’re so delighted to leave the basic sciences behind for an hour, so eager to heal. I always tell them: “If you can get the same satisfaction out of taking an old hemiplegic out of a wet bed, teaching him to walk, to speak so he can be understood, to take care of himself, getting him to the point where he can live a non-institutional life, perhaps getting him a job, and get the same satisfaction as from making some fancy diagnosis of an arcane disease that you may see once in a lifetime, then you’ll make a good doctor. Like it or not, if you go into general medicine, 80% of your patients will have either a chronic or a psychosomatic sickness. (108)

Rusk emphasized that physical disability could be accommodated and that through vocational rehabilitation, many disabled people could live productive lives and be valuable members of the workforce:

When you work with a handicapped person, you’ve got to think of his abilities more than his disabilities. You’ve got to remember that our society doesn’t pay for physical strength. We now have machines to do the heavy labor. Our society really pays for just two things, the skill of your hands and what you have in your head. (105)

The disabled, if properly placed and trained, are good workers with a better production rate, lower accident and absentee rates, and a labor turnover 10 times less than that of normal workers. (110)

In 1955, Rusk received a Christmas card from Adlai Stevenson containing what has been attributed to be the personal prayer of an unknown Confederate soldier in the Civil War (46):

I asked God for strength, that I might achieve
 I was made weak that I might learn humbly to obey . . .
 I asked for health, that I might do greater things
 I was given infirmity, that I might do better things.
 I asked for riches, that I might be happy
 I was given poverty, that I might be wise . . .
 I asked for power, that I might have the praise of men
 I was given weakness, that I might feel the need of
 God . . .
 I asked for all things, that I might enjoy life
 I was given life, that I might enjoy all things . . .
 I got nothing that I asked for
 —but everything I had hoped for
 Almost despite myself,
 my unspoken prayers were answered.
 I am among all men, most richly blessed!

Rusk's disabled patients found personal meaning in this prayer, as did their families, so much so that the father of one young patient had the prayer cast in bronze. The prayer that the boy's father cast in bronze now hangs on the wall in the lobby of the institute Rusk founded (46). The prayer continues to be widely reproduced, and is sometimes referred to as the "Prayer of the Disabled."

Rusk closed his autobiography with a quote from French chemist and microbiologist Louis Pasteur (1822–1895), emphasizing the patient's role in rehabilitation, and in Pasteur's particular case, his successful rehabilitation following a serious stroke:

Ultimately, the success of all rehabilitation depends on the patient himself . . . I can never forget a philosophical quotation that serves as a constant reminder of this truth: "I hold the unconquerable belief that science and peace will triumph over ignorance and war, that nations will come together not to destroy but to construct, and that the future belongs to those who accomplish most for suffering humanity." Those words were spoken by the great 19th-century scientist Louis Pasteur. Few people know that he suffered a serious stroke when he was in his forties . . . He rehabilitated himself—working to the age of seventy three—and many of his greatest scientific achievements came after his stroke. Pasteur's words express what anyone working in this field must feel. To believe in rehabilitation is to believe in humanity. (105)

Rusk never stopped promoting the concept of rehabilitation. As he noted in 1969:

We who have dedicated our lives to rehabilitation medicine must be not only practitioners but teachers, crusaders, and zealots. The stakes are high, not only

for the welfare of the disabled, but also for the future of world understanding If we have the courage and strength and the spirit, this program of rehabilitation medicine will never die but will continue to grow and flourish for the benefit of all mankind. (45)

Rusk received many awards and honors, including three Lasker Awards, the first an Albert Lasker Public Service Award in 1952 "for his pioneering work in the service of the physically disabled and as distinguished rehabilitation mentor to the world," the second an Albert Lasker Award given by the International Society for the Rehabilitation of the Disabled in 1957, and the third an Albert Lasker Medical Journalism Special Award in 1959 "for his editorial leadership in advancing medical research and public health programs in his weekly columns in the *New York Times*" (111,112). In 1966, Rusk was recognized by the American Congress of Physical Medicine and Rehabilitation with a gold medal bearing the inscription: "Physician, teacher, author, inspiration to patients and disciples and a prime mover in the development and spread of medical rehabilitation throughout the world" (111).

In 1981, in the "Year of the Disabled," Rusk—then 80—was nominated for the Nobel Peace Prize. At that time, a reporter for the American Medical Association interviewed Rusk, who was still actively promoting comprehensive rehabilitation.

Although some people, Ronald Reagan among them, call Howard Rusk "The Father of Rehabilitation Medicine," he declines that honor. "Minnesota's Dr. Frank Krusen deserves that title," he says. "He was far ahead of me. He succeeded in getting the AMA to recognize physical medicine as a specialty when most doctors made no bones about brushing it off as a 'social service boondoggle.'" Rusk will admit, however, to being "father, midwife, and pediatrician" to the modern concept of rehabilitation, the radical who argues that physicians should treat the "whole person. Not just the ring finger or toe." . . . Before World War II, physiatrists were concerned almost exclusively with physical and electrical modalities of treating neuromusculoskeletal disease. Under Howard Rusk, rehabilitation medicine has blossomed into a multidisciplinary, in-hospital training program. (108)

Despite Rusk's statement to the contrary, many of his colleagues continued to apply that label to him (3), and to this day the Association of Academic Physiatrists continues to label Rusk the "Father of Rehabilitation Medicine" (and Krusen the "Father of Physical Medicine") (11).

The fully formulated definition of rehabilitation by Rusk, the acknowledged father of comprehensive rehabilitation medicine, is worthwhile recounting:

Rehabilitation is the restoration of the handicapped to the fullest physical, mental, social, and economic usefulness of which they are capable. Frequently, it has

been called “the third phase of medicine”—following preventive medicine, and curative medicine (and surgery). In contrast to “convalescence, wherein the patient is left alone to rest while time and nature do their cures,” medical rehabilitation is a dynamic concept—an active program. The first objective of medical rehabilitation is to eliminate the disability, if that is possible; the second is to reduce or alleviate the disability to the greatest possible degree; and the third, to retrain the person with a residual physical disability “to live and to work within the limits of his disability, but to the hilt of his capabilities.” (46)

At the time of renaming of the Institute of Rehabilitation Medicine as the Rusk Institute in 1984, Rusk noted that he used “the phenomenon of hope” to train people “not just within the limits of their ability, but up to the heights of their latent ability—to help them live the very best lives possible with what is left” (110). Rusk’s framework and focus on treating the “whole person” has been the basis of subsequent programs and developments in the field, and has been incorporated into definitions of the field used by major rehabilitation organizations (11).

EVOLVING CONCEPTS OF DISABILITY AND REHABILITATION SINCE THE 1960s

There have been three fundamentally different approaches to modeling disability: the medical model, the social model, and, more recently, various bio-psycho-social models that incorporate features of both the medical and social frameworks (113–116). The medical model of disability

views disability as a feature of the person, directly caused by disease, trauma or other health condition, which requires medical care provided in the form of individual treatment by professionals. Disability, on this model, calls for medical or other treatment or intervention, to “correct” the problem with the individual. (116)

This medical framework was the foundation of many of the disability-related programs in the United States until the Americans with Disabilities Act (ADA) was passed in 1990:

The [medical] model defines disabling conditions as principally the product of physical and mental impairments that constrain performance. Influenced by this view, health and social agencies provide a mix of services that, for the most part, categorize affected individuals as permanently ill and incapable of meeting their own needs. Therefore, the problems that disability-related programs seek to address are often viewed as inherent to the individual and as independent of society. (115)

People with disabilities, however, have championed the “demedicalization” of disability, and have argued for

recognition that disability is, in large measure, the result of a social environment that does not address the needs of those with physical or mental limitations.

The independent-living and disability-rights movements blame adherence to the medical model for the creation of disability-related programs that foster dependence rather than personal autonomy. Members of these movements correctly argue that disability is the result of a dynamic process involving complex interactions among biological, behavioral, psychological, social, and environmental factors. (115)

The social model of disability, in contrast, “sees disability as a socially-created problem and not at all an attribute of an individual” (113,116). Within this framework, “disability demands a political response, since the problem is created by an unaccommodating physical environment brought about by attitudes and other features of the social environment” (116). Particularly since the 1970s, there has been greater awareness of the social and environmental contributors to disability, facilitated in part by the advocacy of disability rights groups and by court cases and protest actions initiated by disabled individuals seeking basic civil and human rights (117). These actions helped bring about greater societal acceptance of disability, a shift in the federal government’s official objectives to include equal opportunity, independent living, integration, and full participation for all citizens (i.e., a shift “from charity to rights”) as well as the most comprehensive disability rights legislation in history, the ADA of 1990 (117). The ADA included provisions prohibiting employers from discriminating against a disabled person in hiring or promotion if the individual is otherwise qualified for the job, and mandating that businesses make “reasonable accommodations” for disabled workers including job restructuring and modification if required; that federal, state, and local governments and programs be accessible; that public transportation be accessible to handicapped people; and that privately operated public accommodations (e.g., restaurants, hotels, and retail stores) make “reasonable modifications” to ensure accessibility.

Both the medical and social models have value, and both can encourage communication among professionals across different disciplines, facilitate understanding of patients’ problems, and help guide efforts to improve functioning of people with disability. Since the 1960s and 1970s, models of disability and rehabilitation have been developed and refined integrating aspects of both the medical and social frameworks into more balanced bio-psycho-social models (113–116,118–124). These models specifically acknowledge that “whether a person performs a socially expected activity depends not simply on the characteristics of the person but also on the larger context of social and physical environments” (115). As a result, such models help to “set the rehabilitation agenda clearly in a social context while still recognizing that disease has an important influence on patients’ levels of physical activity and social participation and on the process of rehabilitation” (125). Such models also

extend “the boundaries of rehabilitation—from the few conditions where recovery is expected to any condition in which someone experiences disability or handicap secondary to (or as part of) illness” (125).

Unfortunately, the terminology employed in these models has changed over the years, making comparisons difficult and hampering understanding. The term “disability” has variably referred to dysfunction at the level of the person, dysfunction owing to an inadequate social and physical environment, or an entire spectrum of dysfunction affecting organs and organ systems, the person, and the person’s interaction with his or her social and physical environment. In the United States and other countries, there has been a movement away from the use of the word “handicap” (115,126).

The World Health Organization’s Impairments-Disabilities-Handicaps Framework (1980)

In 1980, the World Health Organization (WHO) introduced the *International Classification of Impairments, Disabilities, and Handicaps (ICIDH)*—a tool for the classification of the consequences of disease as a complementary framework for the *International Classification of Diseases (ICD)* (122,127). ICIDH defined the terms “impairment,” “disability,” and “handicap,” and provided a preliminary classification and grading scale for each based on a conceptual framework developed initially in the 1970s by epidemiologist Dr. Philip H.N. Wood (1928–2008) of the University of Manchester Medical School in Manchester, England (122,127). Impairment was considered to represent “exteriorization” of a pathological state (disease), that is, an organ-level disturbance evident through symptoms or signs. Disability was considered “objectification” of impairment, a person-level restriction or lack of ability to perform a normal activity such as personal care or walking. Handicap was considered to represent “socialization” of a disability or impairment: a social disadvantage for an individual that limits or prevents fulfillment of a normal social role such as self-sufficiency. Under this framework, **disease** → **impairment** → **disability** → **handicap**.

ICIDH listed the goals for intervention as they pertain to disability:

1. *Prevention*
2. *Enhancement* (e.g., when activities can be performed unaided but only with difficulty)
3. *Supplementation* (e.g., when activities can be performed only with aid, including the assistance of others)
4. *Substitution* (i.e., when certain activities cannot be performed even with aid) (122).

Under this framework, rehabilitation focuses on the latter three categories (i.e., enhancement, supplementation, and substitution) to minimize handicap.

In many ways, the initial WHO formulation relied heavily on a medical model of disability (115,116), even though it recognized that social factors were inherent in what it

called “handicap” (122). This approach resulted in charges that ICIDH promoted the “medicalization” of disability and failed to adequately address the major impact of social and environmental factors (115,121).

The Institute of Medicine’s “Disabling Process” Framework (1991)

In a 1991 report of the Institute of Medicine (IOM) titled *Disability in America*, the components of the “disabling process” were refined from those initially described by sociologist Saad Z. Nagi of Ohio State University in the 1960s (115,119–121). Under this framework, the disabling process has four major components: pathology, impairment, functional limitation, and disability, with the usual (although not universal) progression being **pathology** → **impairment** → **functional limitation** → **disability**.

There are exceptions to this typical progression:

Although [the model] seems to indicate a unidirectional progression from pathology to impairment to functional limitation to disability, and although a stepwise progression often occurs, progression from one stage to another is not always the case. An individual with a disabling condition might skip over components of the model, for example, when the public’s attitude toward a disfiguring impairment causes no functional limitation but imposes a disability by affecting social interaction. Also, the effects of specific stages in the model can be moderated by such interventions as assistive devices. Similarly, environmental modification (e.g., elimination of physical obstacles and barriers) is an important form of disability prevention . . . (115)

There are clearly overlaps and differences between the IOM model and the earlier WHO model (122). In the IOM model, *pathology* concerns the abnormal interruption or interference of normal bodily structures or processes because of factors (e.g., disease, infection, trauma, and genetic defect) operating at the molecular, cellular, or tissue level. *Impairment* concerns the loss or abnormality of a mental, physiological, or biochemical function at the organ or organ systems level. A *functional limitation* is the impaired ability or inability to perform a specific task at the level of the whole organism, such as walking or climbing a flight of stairs. A *disability* is a limitation in performing roles and tasks expected of an individual within a social and physical environment—an abnormal gap between the individual’s capabilities and the environmental and societal demands.

In the IOM model, the amount of disability a person experiences is directly linked to the “quality of the surrounding environment—for example, whether appropriate and adequate care is accessible and whether a social support network is in place” (118). Thus, a major focus of rehabilitation is minimizing disability by physical and social environmental modifications so that an individual can participate fully in society.

Although to some degree a mixed bio-psycho-social model, the IOM framework is based heavily on a social model of disability:

Disability is the expression of a physical or mental limitation in a social context—the gap between a person’s capabilities and the demands of the environment. People with such functional limitations are not inherently disabled, that is, incapable of carrying out their personal, familial, and social responsibilities. It is the interaction of their physical and mental limitations with social and environmental factors that determines whether they have a disability. Most disability is thus preventable. (115)

Further, the IOM report correctly emphasized that disability prevention can be directed at any of the stages of the disabling process. Even at the disability stage, “efforts can focus on reversal of disability, restoration of function, or prevention of complications (secondary conditions) that can greatly exacerbate existing limitations or lead to new ones” (115). However, the focus of disability prevention was placed heavily on social and environmental modification:

[A]lthough disability can be prevented by improving the functional capacity of the individual—the traditional aim of rehabilitation—this is not the only or perhaps even the most effective method. Disability can be prevented by changing societal attitudes that now restrict employment opportunities for persons with functional limitations, by modifying the buildings in which the people work, or by providing accessible modes of transportation (all of which are components of the ADA). (115)

The IOM’s “Enabling–Disabling Process” Framework (1997)

In 1997, the IOM published a report titled *Enabling America* as a follow-up to and revision of its previous *Disability in America* report from 1991 (115,118). The 1997 report revised the earlier “Disabling Process” model to formally recognize that the focus of rehabilitative efforts is to assist the individual in reversing the disabling process through an “enabling process”:

[R]ehabilitation is the process by which physical, sensory, and mental capacities are restored or developed in (and for) people with disabling conditions—reversing what has been called the disabling process, and may therefore be called the *enabling process*. This is achieved not only through functional changes in the person (e.g., development of compensatory muscular strength, use of prosthetic limbs, and treatment of posttraumatic behavioral disturbances) but also through changes in the physical and social environments that surround them (e.g., reductions in architectural and attitudinal barriers). (118)

A person without disability is considered to be “fully integrated into society” and has access to social opportunities (e.g., education, employment, and parenthood) and physical space, whereas a person with a potentially disabling condition has increased needs that can manifest as a true disability if the social and physical environment are inadequate for these needs. The enabling (or rehabilitative) process attempts to counteract the disabling process by functional restoration and environmental modification.

The WHO’s Functioning–Disability–Health Framework (2001)

The initial version of ICIDH promulgated by the WHO in 1980 was widely adopted around the world and was very influential in stimulating research as well as discussion of the best framework for considering disability. Beginning in 1995, ICIDH underwent an exhaustive revision process, with comments from more than 80 countries, field tests in 42 countries, and input from scientists, disability groups, and other non-governmental organizations. The culmination of this revision process was the publication of the *International Classification of Functioning, Disability and Health* (ICF) in 2001 (123,124).

In a shift from the previous WHO formulation, ICF emphasized health and functioning, rather than disability:

Previously, disability began where health ended; once you were disabled, you were in a separate category. We want to get away from this kind of thinking This is a radical shift. From emphasizing people’s disabilities, we now focus on their level of health. ICF puts the notions of “health” and “disability” in a new light. It acknowledges that every human being can experience a decrement in health and thereby experience some disability. ICF thus “mainstreams” the experience of disability and recognizes it as a universal human experience. By shifting the focus from cause to impact it places all health conditions on an equal footing allowing them to be compared using a common metric—the ruler of health and disability. (116)

“Functioning” in the ICF framework is specifically structured around two broad components: (a) body functions and structure; and (b) activities and participation (i.e., involvement in a life situation). Further, participation can be viewed from either a performance perspective (i.e., what an individual does in the current environment) or a capacity perspective (i.e., what an individual can do in an optimized environment). The discrepancy between capacity and performance, the capacity–performance gap, suggests what could be changed in the current environment to improve performance (128).

ICF is based on a bio-psycho-social model that integrates medical and social frameworks of disability from earlier models:

Disability is always an interaction between features of the person and features of the overall context in which

the person lives, but some aspects of disability are almost entirely internal to the person, while another aspect is almost entirely external. In other words, both medical and social responses are appropriate to the problems associated with disability; we cannot wholly reject either kind of intervention [In] ICF disability and functioning are viewed as outcomes of interactions between health conditions (diseases, disorders and injuries) and contextual factors. Among the contextual factors are external environmental factors (e.g., social attitudes, architectural characteristics, legal and social structures, as well as climate, terrain, and so forth); and internal personal factors (116)

Health conditions (i.e., diseases, disorders, and injuries) lead to impairments (i.e., problems in body functions and structure) that may be associated with activity limitations (i.e., difficulties in executing activities), and/or participation restrictions (i.e., problems with involvement in life situations). Thus, a stroke (a health condition) can cause hemiparesis (an impairment), which is associated with impaired mobility (an activity limitation), and which may cause inability to use mass transit, find a job, and so on (participation restrictions). Under this framework, the impairments, activity limitations, and participation restrictions are different categories subsumed under the broad umbrella of “disability.” This spectrum of disability is dependent on further interactions with the underlying health condition, and also with contextual factors, including environmental and personal factors. The ICF framework can also be linked to different treatment, rehabilitation, and social/environmental interventions and prevention approaches (116).

EVOLUTION OF STROKE REHABILITATION

In the late 19th and early 20th centuries, most medical investigations concerning stroke dealt with clinical phenomenology, pathology, clinical–pathologic correlation, and pathophysiology. At this time, very little was attempted as far as retraining or rehabilitation of stroke victims was concerned. Although a few scattered prophets of rehabilitation concepts can retrospectively be identified during this period, they made relatively little impact and their proposed treatments were, at best, haphazardly employed (129,130).

Some of the antecedents of rehabilitation available in the early 20th century included, for example, the tedious repetition of reading, spelling, and repeating words for aphasia; passive movement of severely paralyzed limbs or programs of exercises for less severe paralysis; various orthotic and assistive devices such as splints to prevent contractures, light braces for support, canes (Figure 1.13) (131–135), crutches (Figure 1.14) (131–135), and wheelchairs; attempts to use electrical stimulation to facilitate recovery or prevent muscle wasting; and various surgical procedures to try to limit contractures or spasticity (129,130). Even in the 1950s, as noted

by Barrow and Metts (1986), the prevailing attitude was one of therapeutic nihilism born of hopelessness, compounded by a lack of resources and trained staff:

As late as the mid '50s, the attitude of both doctors and families of patients with a completed stroke was one of hopelessness. The patients were placed in a nursing home or in a back room, usually at complete bed rest, and they were waited on and pampered as invalids. Under these conditions, the patients usually deteriorated rapidly and complications of decubitus ulcers, muscle spasms, atrophy, and infections were frequent. Other factors of importance at this time were the lack of physical therapy departments in the hospitals . . . and the unavailability of outpatient physical therapy resources. Even the rehabilitation facilities such as Warm Springs, Georgia, had little activity in the field of stroke rehabilitation. (130)

Rehabilitation of stroke victims was not systematically developed until the second half of the 20th century (129,130). In the 1970s and 1980s, the stroke rehabilitation team approach began to develop and spread; stroke units, sometimes employing a seamless transition between acute care and rehabilitation, were developed in larger hospitals in urban areas; and outpatient rehabilitation resources were developed including services provided by health departments, visiting nurse associations, free-standing day care centers, and hospital-associated and independent physical therapy practices (130). The 1970s and 1980s also saw the beginning of an explosion in stroke rehabilitation research, with an exponential escalation in the use of randomized trials of stroke rehabilitation therapies, particularly since the 1990s (136). Both the total number of journal articles and the number of journal articles reporting the results of randomized clinical trials have grown exponentially, although the rate of growth for randomized trials of stroke rehabilitation has been greater since the 1970s (DJ Lanska, unpublished analyses, 2007). Although spontaneous recovery accounts for most of the improvement in functional ability following stroke (137), a growing body of evidence since the 1990s supports a modest and marginal, but clinically important, benefit of stroke rehabilitation, generally for patients with, at most, moderate disability (138–143).

Organized Inpatient Multidisciplinary Stroke Rehabilitation

Since the 1970s, and particularly since the 1990s, it has become clear that organized inpatient multidisciplinary rehabilitation in the postacute period provides clinically important benefits (138–143). Most data supporting the clinical benefits of inpatient stroke rehabilitation are based on studies of comprehensive stroke units (that provide acute stroke care and rehabilitation) or rehabilitation stroke units (dedicated to rehabilitative care of postacute patients with stroke), rather than the more common mixed rehabilitation

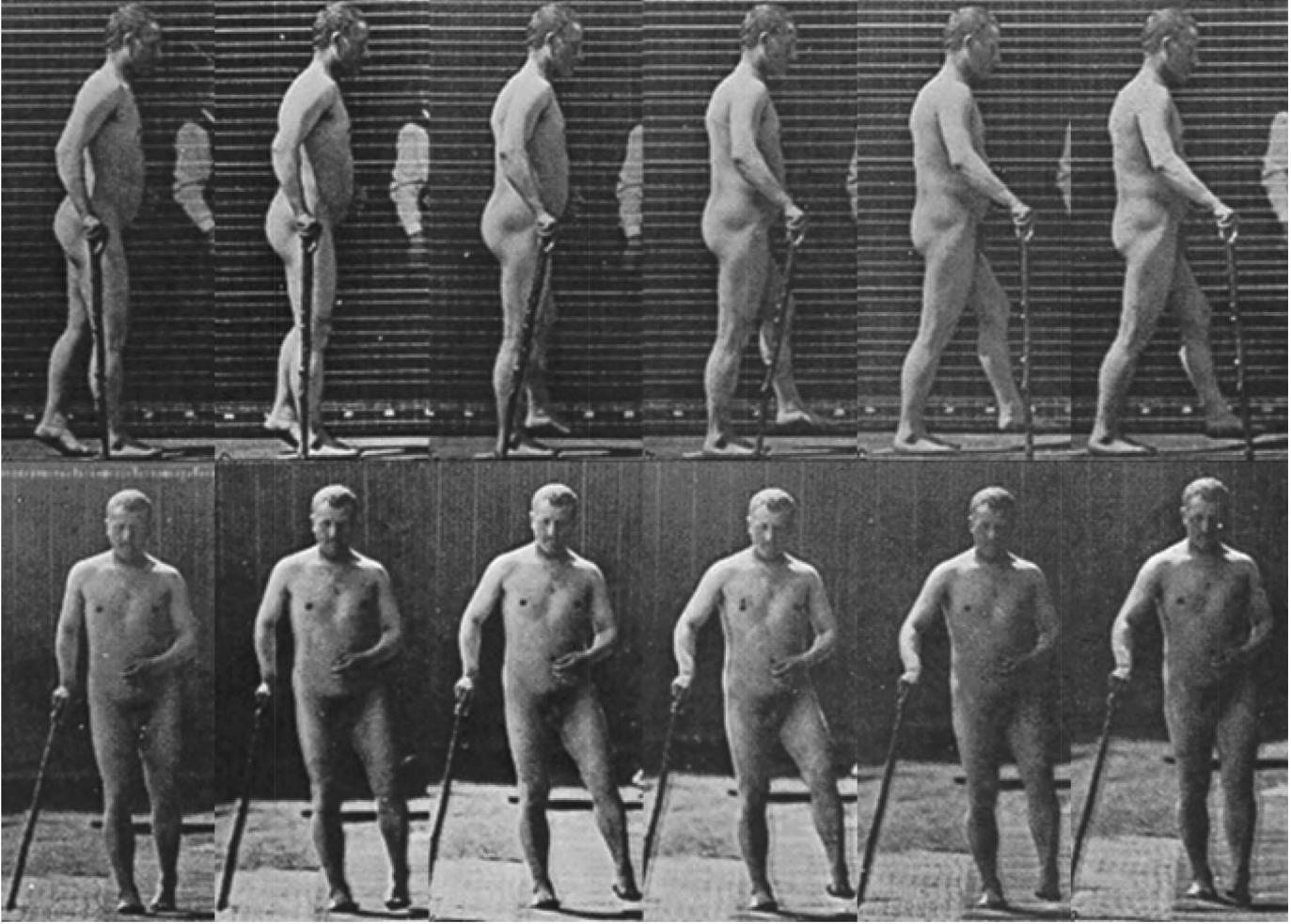


FIGURE 1.13 In the late 1870s and 1880s, prior to the development of movie cameras or projectors, American photographer Eadweard Muybridge (1830–1904) photographed sequential images of people and animals in motion, using arrays of sequentially triggered single-image cameras. In 1885, Philadelphia neurologist Francis Dercum (1856–1931) collaborated with Muybridge at the University of Pennsylvania. This figure shows sequential images of lateral and frontal views from a portion of Muybridge’s “Plate 552. Spastic, walking with cane” (Source: From Ref. 133). This sequence shows a man with a dense spastic left hemiparesis with the arm held in a flexed posture. As noted by Dercum, “the paralyzed leg is quite stiff, little or no flexion taking place at the knee” Circumduction of the left leg (seen especially on the frontal views) is quite prominent, with the leg first swinging outward during forward motion and then returning toward the midline in an arc. Notice as well, the equinovarus deformity, or as Dercum commented, “the exaggeration of the normal tendency of bringing the outer edge of the foot to the ground in advance of the sole” (Source: From Refs. 131, 132, and 133).

units (that provide stroke rehabilitation in a mixed rehabilitation setting) (142). Stroke patients who receive inpatient rehabilitation provided by a coordinated multidisciplinary team are more likely to recover the ability to perform activities of daily living, more likely to return to the community, and less likely to die—results that are fairly robust in different meta-analyses and across recent controlled trials (140,144–151). A Danish population-based study comparing two communities—one where care was provided in a dedicated comprehensive stroke unit with both acute care and rehabilitation care, and the other in which care was provided on general medical and neurologic wards—found that stroke

unit care reduced the length of hospital stay by 30%, reduced the risk of discharge to nursing home by 40%, and reduced the relative risk of death by 50% (140). In a systematic review of 9 trials recruiting 1,437 patients, Langhorne and Duncan found that for every 100 patients who received organized inpatient multidisciplinary rehabilitation, 5 more returned home in an independent state compared to those who do not receive such care (141). Functional, independence, and survival benefits to those who underwent early multidisciplinary stroke rehabilitation after stroke are sustained even 5 to 10 years after stroke (152–156). Patients with moderate or severe strokes appear to benefit the most (150).

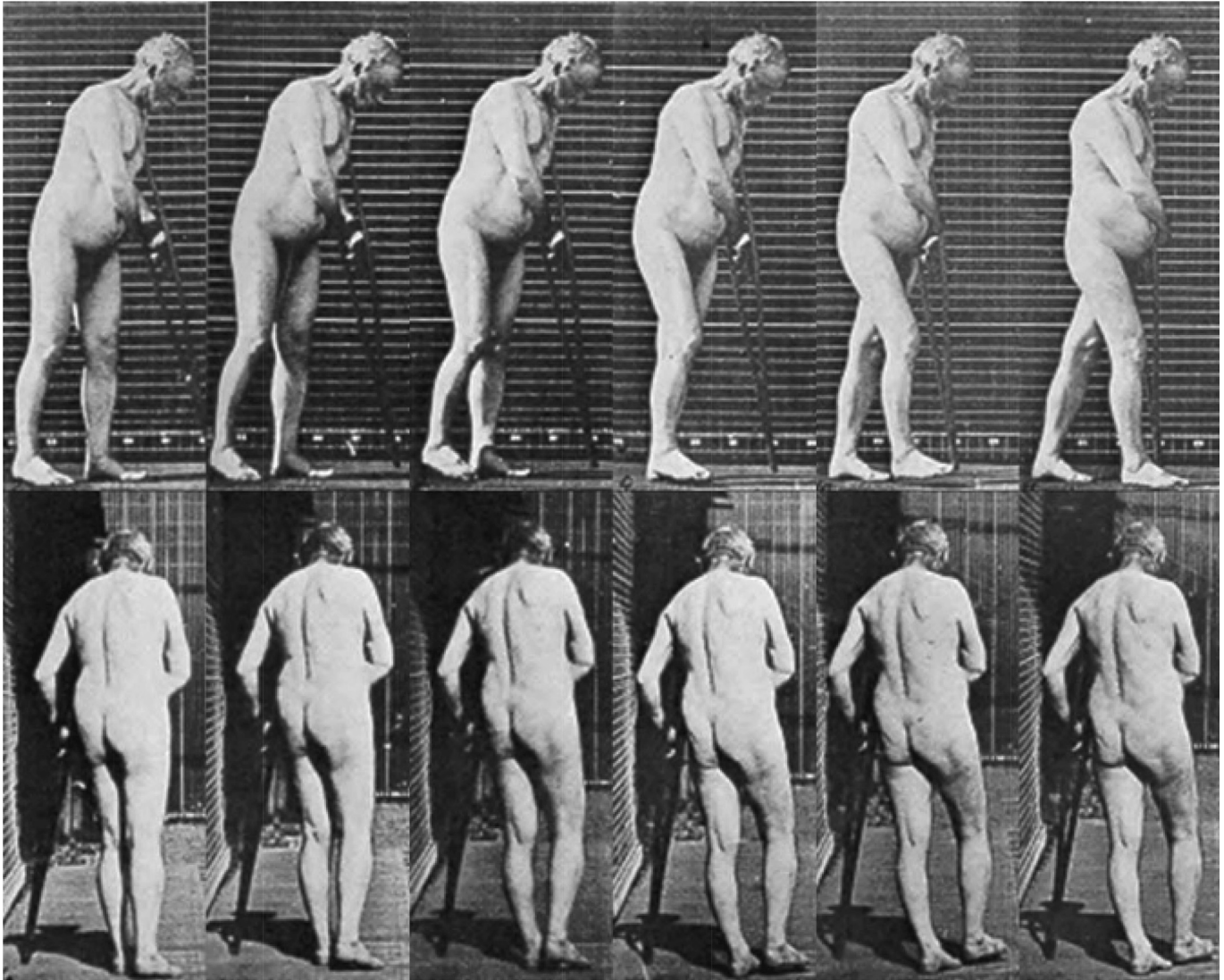


FIGURE 1.14 Sequential images of lateral and posterior views from a portion of Muybridge's "Plate 547. Spastic, walking with crutch" taken in 1885 (Source: From Ref. 134). This shows an elderly man with a dense spastic right hemiparesis with the arm held in a flexed posture while using a crutch to walk. As noted by Dercum, "the paralyzed leg is quite stiff, little or no flexion taking place at the knee . . . [The foot is] raised from the ground by the enormous swaying of the trunk toward the sound side, to which additional support is given to receive the sway by means of the crutch." See the legend for Figure 1.4 for further details (Source: From Refs. 131, 132, and 133).

Even where evidence supports a clinical benefit of stroke rehabilitation, it has generally been unclear which specific factors, including which therapies or combinations of therapies, among the entire package of individualized treatments for a given patient are most important for providing benefit (142,157–159). Although data supporting the value of individual team members in the multidisciplinary team are limited, most authorities and clinical care guidelines have advocated a broad team composition, including physicians, nurses, physical therapists, occupational therapists, speech therapists, and social workers (140). Although available studies are limited, the intensity of rehabilitation services is a modest predictor of recovery among stroke patients (151,160–164), as is, particularly, an early start to intensive

treatment (158,159). It has also been unclear to what extent findings of randomized clinical trials could be generalized to the routine clinical setting: the limited available data suggest that the routine clinical rehabilitation setting can reproduce the benefits of stroke rehabilitation units in controlled trials and meta-analyses, but the magnitude of benefit is smaller outside of the formalized experimental setting (165). Inpatient rehabilitation is also expensive, and the limited available cost-benefit analyses have not strongly supported the cost-effectiveness of inpatient stroke rehabilitation overall (166–168), making it imperative to carefully select patients who will benefit most from such intensive care (169), and also to identify the least expensive care settings that will provide maximum clinical benefit to individual patients (170).

Clinical Pathways

Integrated care pathways have not been shown to improve the outcome of inpatient stroke rehabilitation (171–178). In fact, care pathways for rehabilitation programs have most often resulted simply in decreased patient satisfaction (171–174,178), and some studies have actually reported slower recovery and lower quality of life among patients receiving rehabilitation as part of an integrated care pathway as opposed to conventional multidisciplinary rehabilitative care (171,175). As noted by Teasell, “This apparent paradox may signify the importance of using evidence or guidelines to assist rehabilitation clinicians in individualizing the rehab of stroke patients as opposed to a ‘one size fits all’ approach” (178). Furthermore, despite potential benefits, many clinical pathway programs for acute or rehabilitation care of stroke fail because of inadequate planning and implementation (173,174). Effective implementation of such programs requires strong administrative and medical staff leadership, active participation of all clinical disciplines involved in the rehabilitative care of patients on the pathway, provision of regular feedback to clinicians, sufficient resources, improved (and often more detailed) documentation, incorporation of the entire rehabilitation period of care into the pathways, integration with ongoing quality and utilization management programs, and periodic evaluation and modification (173,174).

Specific Therapies

Based on expert opinion and limited controlled trial data, physical therapy is modestly beneficial for stroke patients (159,164,179,180). However, there continues to be considerable variation in the beliefs (181) and treatment approaches (182,183) of physical therapists concerning the treatment of stroke patients, in part a function of the treatment approach in vogue when the physical therapists were trained (184). Particularly since the 1950s, several different physical therapy approaches have been developed and applied in the treatment of stroke patients (139,180–194). Some physical therapists advocate and apply Bobath’s “neuro-developmental” approach developed by physiotherapist Berta Bobath (c. 1908–c. 1991) and her husband, psychiatrist and neuro-physiologist Karel Bobath, MD (c. 1906–c. 1991) (187), both Jewish refugees from Nazi Germany to England; the “motor re-learning programme” of Janet H. Carr, MA, EdD, and Roberta B. Sheperd, MA, EdD (188); Swedish physiotherapist Signe Brunnström’s approach utilizing abnormal synergies (186); and various others. Controlled trial data are as yet inconsistent, and no clearly better approach has been identified from among the available approaches for the physical therapy of stroke patients (180,183). Progressive resistance exercises several times a week can help improve strength and functional abilities in patients with adequate motor control (138,195). The intensity of therapy initiated early seems to be important in maximizing the degree of functional improvement (161–164).

Based on the results of systematic reviews, comprehensive occupational therapy is modestly beneficial in improving activities of daily living and social participation among stroke patients (196,197), although there is limited or insufficient evidence supporting many specific occupational therapy interventions, including provision of splints for decreasing muscle tone (196,198). Even when provided in the community, occupational therapy can improve basic activities of daily living, as well as domestic and leisure skills, as indicated by systematic reviews (196,197). Different task-oriented practice strategies can be helpful, especially if intensive training in specific skills is provided (138,161–163,196). Constraint-induced-movement therapy—based on the idea that “learned nonuse” of a weak arm develops because of the greater effort required to use it—seeks to encourage the use of the weak arm and promote helpful cerebral plasticity (138,199); this approach can be helpful in increasing the amount and efficiency of the use of the weak arm in the relatively small subset of patients with fairly good motor control to begin with (138,200–202).

Available data from randomized controlled trials concerning the efficacy of speech therapy in stroke rehabilitation are limited and not entirely consistent (203), with some trials supporting a modest benefit within the first 3 to 6 months after stroke (160,204,205), and others finding lesser or no significant benefit for most patients (206–208). A greater intensity of therapy in the first several months poststroke seems to be an important factor in the degree of improvement (160,203,209).

Early Supported Discharge

In most countries, into the 1990s, stroke patients were treated initially in the hospital, followed by a variable period of inpatient rehabilitation, but rehabilitation often stopped after discharge (210). In some countries, early supported discharge (ESD) approaches have been developed since the 1990s that shorten the period of acute hospital stay and provide rehabilitation services beginning in the hospital and continuing for the first few weeks at home. Proponents have claimed that this approach is not only less costly, but can also improve care by providing “seamless service” spanning inpatient and home care environments; however, until recently there were limited data to evaluate such claims (210). Single-blind randomized controlled trials have been reported from the United Kingdom, Scandinavia, Australia, and Canada (211–224). Although some studies of ESD have not identified any significant benefits of this approach (213), others have reported similar efficacy compared with traditional inpatient rehabilitation along with significant cost savings (212,224); reductions in total hospitalization (of approximately 50%) (217,218,220); reduction in use of inpatient rehabilitation beds (211); improved patient satisfaction (214,217,220); less caregiver stress (221); and, in some cases, improved performance of activities of daily living (215,218,219,222), and longer sustained noninstitutional care (215). In one well-designed study

from Norway, stroke patients who received ESD rehabilitation services spent less time in hospital and were also more likely to be independent and to be living at home after one year (215). As suggested by Langhorne, presumably “the ESD service has improved the patient’s ability to regain normal activities despite residual impairment. In particular, the patient’s own home is probably the best place for him or her to relearn the skills needed to function in that environment” (210). A home environment for rehabilitation may also facilitate patients with moderate neurologic impairments taking greater responsibility and exercising a greater influence over their own rehabilitation (223). A systematic review of the economic costs of different settings of rehabilitation care found “‘moderate’ evidence that ESD services provide care at modestly lower total costs than usual care for stroke patients with mild or moderate disability” (166).

Outpatient Rehabilitation

The role of outpatient rehabilitation services (i.e., therapy-based rehabilitation services targeted at stroke patients living at home) has only recently been studied in any detail, and the results remain less certain than in the case of traditional inpatient multidisciplinary stroke rehabilitation (225–229). This is complicated by differences in the types of community-based rehabilitation provided, the setting in which such care is provided (day hospital versus the home), and the clinical circumstances for which this approach is used instead of traditional inpatient rehabilitation (228,229). Several studies have evaluated the use of day hospital rehabilitation care with inconsistent results compared with either inpatient multidisciplinary care or home care (230–232). Costs are generally higher for day hospital rehabilitation than for home care (230,232), but not universally so (231). Functional outcomes for day hospital rehabilitation are generally similar to rehabilitation provided in other settings (230,231), although one study reported better functional outcomes with day hospital rehabilitation than with home care (232). Nevertheless, preliminary results suggest that some therapy-based rehabilitation services provided in the home can result in a greater ability to perform activities of daily living and reduce the risk of deterioration in ability compared with conventional care (i.e., normal practice or no routine intervention) (225–229). Other studies have indicated no benefit for some outpatient services that were not primarily therapy-based, including the use of an outreach nursing support program (233,234). Further studies are needed to define the most appropriate level of service delivery, the most effective services and interventions, and their cost-effectiveness compared with other approaches (225). At present, there is “insufficient” evidence concerning the economic costs of community-based rehabilitation (166).

Caregiver Training

Family involvement in support of the poststroke patient has long been recognized as a strong independent predictor of

discharge to home as opposed to an institution (169). Because the degree of family involvement can sometimes be influenced by the rehabilitation team, family and caregiver training has been a major target of therapeutic intervention, and is being increasingly recognized as a predictor of functional outcome as well (169). Caregiver training during the rehabilitation of stroke patients can reduce the cost of care and improve the overall quality of life among caregivers, even as long as a year poststroke (235,236). Problem-solving training, including an in-home visit and subsequent telephone contacts by a trained nurse, may also be useful for family caregivers of stroke survivors even after the latter’s discharge from rehabilitation (237). Caregiver training and education may help caregivers be better prepared to deal with issues, facilitate development of caregiver problem-solving skills, lessen caregiver stress and depression, minimize secondary complications among the patients, and facilitate patient motor tasks that promote functional improvements and lessen the risk of further functional declines (e.g., safe swallowing and walking for exercise) (138,237).

Gaps in Theoretical Foundations and Practical Implementation Remain

The development of stroke rehabilitation concepts is still limited, with the recognition in the field that many of the therapeutic approaches currently employed have, at best, limited benefit in a select subgroup of patients; that much of the theoretical justification for different rehabilitation models and approaches remains speculative; and that there is no overall foundation for an accepted “theory of rehabilitation” that could help to prevent fragmentation and division, provide coherence, focus research and development in this area, and facilitate competition for limited research funding (138,142,238,239). Moreover, because rehabilitation interventions are typically multidisciplinary, multifaceted, and customized to the individual patient’s needs and goals, they are, in practice, difficult to standardize, and therefore difficult to measure and compare (138,142,238). Available treatment studies are further complicated by the heterogeneity of impairments and disabilities of the patients studied, poor descriptions of the specific treatments administered, inadequate controls, lack of blinding, small sample sizes, and insensitive outcome measures (138).

Current expert consensus has strongly supported the importance of integrating rehabilitation into systems of care to ensure that all patients who could potentially benefit from appropriate stroke care and rehabilitation are provided with the appropriate treatment in a time frame that will maximize recovery and minimize disability (151). According to the American Stroke Association’s Task Force on the Development of Stroke Systems:

Stroke rehabilitation involves a combined and coordinated use of medical, social, educational, and vocational measures for retraining individuals to reach their maximal physical, psychological, social, vocational, and a

vocational potential. Specifically, stroke rehabilitation programs are provided to optimize neurologic recovery, teach compensatory strategies for residual deficits, teach activities of daily living (ADLs) and skills required for community living, and provide psychosocial and medical interventions to manage depression. The team provides patient and family education about the medical management of post-stroke complications and secondary stroke prevention Practice guidelines for rehabilitation are well established in this area, although patients often do not receive a level of care that is consistent with these guidelines The intensity of rehabilitation services often is a critical determinant in the recovery of stroke patients. The use of coordinated, multidisciplinary stroke rehabilitation teams has been shown to diminish mortality rates for stroke patients. In addition, stroke patients who receive care in an inpatient rehabilitation facility are more likely to return to the community and to recover their ability to perform ADLs Building stroke systems throughout the United States is the critical next step in improving patient outcomes in the prevention, treatment, and rehabilitation of stroke. The current fragmented approach to stroke care in most regions of the United States provides inadequate linkages and coordination among the fundamental components of stroke care. (151)

Practice guidelines are now available for stroke rehabilitation (240–242), but in many cases patients do not receive care consistent with the guidelines (142,151,243,244). Further, there are sociodemographic inequalities in the use of rehabilitation services, suggesting inappropriate underuse among certain populations (245).

Even when patients receive inpatient stroke rehabilitation, they spend only a small amount of their inpatient stay participating in potentially rehabilitative activities, and this low intensity of therapy is less likely to produce beneficial outcomes (138,142,227,246). In an observational behavioral mapping study of five stroke units, patients had therapist contact during only 5% of the day, participated in minimal or moderate therapeutic activity for less than 13% of the therapeutic day (8 a.m. to 5 p.m.), and were resting in bed 53% of the time and alone 60% of the time (247). Poor participation in therapeutic activities is common during inpatient rehabilitation, and is associated with longer lengths of inpatient stay and lower degrees of improvement in functional performance (248). In addition, for financial or policy reasons, formal therapy is typically stopped when there are no evident qualitative gains in function after several weeks of treatment, even though, as Dobkin notes: “A plateau in recovery . . . does not necessarily imply a diminished capacity for further gains in physical speed or precision or in learning a new task” (138).

Furthermore, despite modern treatment and multidisciplinary rehabilitation, perhaps half of the patients with stroke are ultimately discharged home with serious, persistent neurologic impairments, functional limitations, and, often, disability resulting from inadequate environmental supports (249). Stroke survivors (whether residing at home

or in institutional care environments) are prone to multiple secondary conditions that further erode health, including social isolation, depression, physical inactivity, painful joint contractures, deep venous thromboses and pulmonary emboli, decubitus ulcers, incontinence, aspiration pneumonia, inadequate nutrition, falls, hip fractures, and seizures. Such patients are often frail and susceptible to aggravation of existing disease or development of new illness, with resulting functional decline, high resource utilization, high rates of rehospitalization, significant added morbidity, and a high risk of death within the first year after stroke onset. Indeed, in the United States, approximately one-fifth of stroke patients die in the first month after stroke, a quarter within 2 months, and a third within 6 months (250). Patients and caregivers can benefit from a close liaison between inpatient and community care programs, and also from continuing professional support and counseling after discharge following a stroke (249).

Further studies are needed to define the most appropriate level of service delivery for stroke rehabilitation, the most effective services and interventions among the “complex packages of care” that comprise current rehabilitation programs, and the most cost-effective stroke rehabilitation service among the different types available (142,225).

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