When Walking Fails: Mobility Problems of Adults with Chronic Conditions Suggests Policy Solutions

Study of the problems of health care access faced by people with impaired ambulation

SUMMARY

Lisa I. Iezzoni, MD, MSc, of Beth Israel Deaconess Medical Center wrote, When Walking Fails: Mobility Problems of Adults with Chronic Conditions, a book about how mobility problems affect people's lives and how health care and other policies help or hinder their independence, published by University of California Press in 2003.

The project was part of the Robert Wood Johnson Foundation's (RWJF) Investigator Awards in Health Policy Research program (for more information see Program Results).

Key Findings

Iezzoni reported the following key findings in her book and in several journal articles:

- About 19 million adults who live outside nursing homes or other institutions say they have at least some difficulty walking or use a mobility aid.
  - Mobility difficulties are not exclusively conditions of old age.

- People with mobility difficulties are more likely to have health insurance than those without such problems.
  - Medicare and health insurers often have coverage policies that prevent people with disabilities from obtaining assistive devices and regaining their independence.

- The most common causes of mobility problems are arthritis and other joint problems, back problems, accidental falls, heart disease, motor vehicle accidents, and chronic lung disease.
  - People with mobility problems are more likely to be obese.

- Many people who use wheelchairs or scooters do not view themselves as disabled.
Whether to start using a wheelchair or scooter is a critical decision for people who have progressive difficulty in walking.

- Primary care physicians are generally poorly trained to recognize physical disabilities and to refer patients to appropriate rehabilitation specialists and assistive technology.
  - Physicians also carry misconceptions about the role a wheelchair might play in patients' lives.
- People with mobility problems face barriers getting into and around health care settings.

**Funding**

RWJF supported Iezzoni's work with $235,756 in funding between March 1997 and February 2000.

**CONTEXT**

The Robert Wood Johnson Foundation (RWJF) has supported the Investigator Awards in Health Policy Research program since 1992. The program serves as one of RWJF’s main vehicles for funding research on broad health policy issues. Investigator Awards is an ongoing program authorized at up to $39 million. The program aims to build the capacity of the health policy field by offering general research support for innovative ideas that are unlikely to be funded elsewhere, and in so doing to attract and retain the field's intellectual talent.

Funded projects have explored such varied topics as health risk and disease prevention, the determinants of health and disparities among population groups, adolescent violence, firearms and tobacco policies, the effects of managed care, the patient-provider relationship, medical technology, patient safety, the policy-making process, and public and private financing programs.

Investigators have also examined public health reporting, accountability, child health policy and long-term care delivery.

**THE PROJECT**

Soon after enrolling at Harvard Medical School in 1980, Iezzoni was diagnosed with multiple sclerosis. After graduation, she became a health services researcher, traveling frequently for her work. Using a battery-powered scooter to get around, Iezzoni found that people frequently approached her with stories about mobility problems that either they or their family members or friends were experiencing. She soon realized that many people were not getting their questions answered by health professionals.
RWJF gave Iezzoni an *Investigators Award* grant to conduct research for a book about how mobility difficulties affect people's daily lives and how policies, especially those involving health care delivery and payment, affect people's ability to remain as independent as possible.

In the course of her research, Iezzoni and her colleagues interviewed 56 people who have difficulty walking, 38 clinicians (internists, nurses, physical and occupational therapists and social workers) and more than 20 others, including health insurance representatives, patient advocates, industry vendors and medical association representatives.

Iezzoni's book, *When Walking Fails: Mobility Problems of Adults with Chronic Conditions* (University of California Press, 2003), features the stories of the people she interviewed, with details about their backgrounds, their home lives and how their mobility problems affect their families, careers and expectations for the future.

She weaves together the experiences of people with mobility problems and federal government data on disabilities to paint a picture of those with difficulty walking and the problems they face in everyday living, including working with their doctors.

The book explains who has mobility problems and why, and details the myriad ways in which being unable to walk affects people—physically, emotionally, in their relationships and in going about their everyday activities. Iezzoni identifies strategies for improving one's mobility, talks about the pros and cons of using wheelchairs and powered scooters, and offers suggestions to help in navigating insurance company policies.

**FINDINGS**

Iezzoni reported the following findings in *When Walking Fails: Mobility Problems of Adults with Chronic Conditions* and several journal articles:

- About 19 million adults who live outside nursing homes or other institutions—just over 10 percent of the U.S. adult population—say they have at least some difficulty walking or use a mobility aid, such as crutches, a walker or a wheelchair. Almost 6 million adults (3%) report either using a wheelchair or scooter or being unable to walk three blocks, climb 10 stairs or stand for 20 minutes. About 88 percent of those who have difficulty walking say these problems will last more than a year.

- Mobility difficulties are not exclusively conditions of old age. The average age when problems start is 52 for people with minor or moderate difficulties and 58 for those with major difficulty. About 10 percent of whites and Hispanics report problems, as do 15 percent of African Americans. People with mobility problems are much more likely than those without to have a high school education or less, to live alone and to be poor and unemployed.
People with mobility difficulties are more likely to have health insurance than those without such problems, but significant numbers of them are uninsured. Uninsurance rates are 12.8 percent of people with minor mobility problems, 13.9 percent of those with moderate impairments and 7.1 percent of those with major difficulties.

The most common causes of mobility problems are arthritis and other joint problems, back problems, accidental falls, heart disease, motor vehicle accidents, and chronic lung disease.

People with mobility problems are more likely to be obese (29.4% of people with major mobility problems compared with 15.2% of people without problems).

Many people who use wheelchairs or scooters do not view themselves as disabled. In Iezzoni's interviews, even people with significant mobility difficulties did not see themselves as disabled but instead emphasized their stoicism, their efforts to remain independent, and their perceptions of not being as "badly off" as some other people.

Whether to start using a wheelchair or scooter is a critical decision for people who have progressive difficulty in walking. Some people who can still walk see using wheelchairs or scooters as an unacceptable admission of dependence. For other people, using a wheelchair can restore their sense of independence and control.

Primary care physicians are generally poorly trained to recognize physical disabilities and to refer patients to appropriate rehabilitation specialists and assistive technology. In medical school or residencies, few physicians are taught about functional assessments of mobility or appropriate interventions.

Physicians also carry misconceptions about the role a wheelchair might play in patients' lives, sometimes viewing the wheelchair as a means of creating dependence rather than independence. In her book, Iezzoni describes a woman in her 40s who had contracted polio as a toddler. When she started falling frequently and asked her physician to prescribe a power wheelchair he refused to do so, fearing that once she started to use it, she would stop walking. From her viewpoint, however, the wheelchair was a safety issue—preventing risk of injury from dangerous falls—and a way to maximize her independence.

People with mobility problems face barriers getting into and around health care settings. Office doors do not have automatic openers, examining rooms do not have adjustable examination tables, and other obstacles also make navigation difficult and sometimes even dangerous. One patient described a physician's office (which met state and federal disability building codes) where she could not get her wheelchair through the clinic doors and which had no railings along the wall for her to hold onto.

Medicare and health insurers often have coverage policies that prevent people with disabilities from obtaining assistive devices and regaining their independence. Examples include vague medical necessity policies, limited coverage of mobility aids,
the requirement that people must prove that they are "homebound," and constraints on
the use of rehabilitative services to maintain physical function or prevent its decline.

**Recommendations**

In *When Walking Fails*, Iezzoni offered the following recommendations:

- Primary care physicians who treat patients with walking impairments should have
  more training, better assessment tools, and closer ties to rehabilitation resources.
  Physicians should also make functional assessments of patients an integral part of the
  treatment process. Better treatment may require physicians, particularly primary care
  physicians, to develop referral networks to other health care providers who are trained
  in working with people who have walking difficulties.

- Organizations that purchase and design insurance packages must rethink their benefit
  designs and provide greater choice for consumers purchasing assistive devices. Better
  front-end coverage of physical and occupational therapy, low-cost home
  modifications (such as grab bars and railings), and mobility aids could actually save
  insurers money by preventing hip fractures and other medical problems.

- People with mobility problems need access to a one-stop service, such as a "mobility
  mart," which could provide physical and occupational therapists, peer counselors and
  support groups, health insurance specialists, diverse mobility aids, information about
  community resources, and referrals to health care providers, among other aids. These
  marts should also allow "test drives" of wheelchairs and rental periods as standard
  practice.

**Communications**

As of June 2004, *When Walking Fails* had sold 3,098 copies. Private donations allowed
Iezzoni to purchase an additional 5,700 copies. She mailed copies to the 1,800 members
of the Society of General Internal Medicine, who are internists at academic medical
centers. Other copies have been distributed free at primary care and specialty clinics at
Beth Israel Deaconess Medical Center in Boston.

Iezzoni also wrote several articles about her research for journals such as *Journal of the
American Medical Association*, *Health Affairs*, and *Annals of Internal Medicine*. See the
Bibliography for details. The national program office features Iezzoni's work on its
website.

**AFTERWARD**

Quality and Access for People with Disabilities*, Oxford University Press (2006), about
improving the quality of care for people with sensory and physical difficulties, including
people who are deaf, hard of hearing, blind and have trouble walking.
BIBLIOGRAPHY

(Current as of date of the report; as provided by the grantee organization; not verified by RWJF; items not available from RWJF.)

Books


Book Chapters


Articles


