

Chapter 12

Disability in Diabetes

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SUMMARY

The public health impact of diabetes can be evaluated from a number of perspectives, one of which is the morbidity associated with the disease. Disability is a broad-based concept that often illustrates this morbidity. Disability affects large numbers of persons with diabetes in the United States, with estimates ranging from 20%-50% of the diabetic population. Persons with diabetes, in general, report rates of disability that are substantially higher than those reported by the general U.S. population. Reported activity limitations (non-insulin-dependent diabetes mellitus (NIDDM) 50.2%, insulin-dependent diabetes mellitus (IDDM) 42.3%, nondiabetic, 16.1%) and restricted activity days (NIDDM, 22.4%; IDDM, 21.3%; nondiabetic, 10.3%) were two to three times higher among persons with diabetes surveyed in the 1989 National Health Interview Survey (NHIS). Persons with IDDM from the Children's Hospital of Pittsburgh (CHP) IDDM Registry were seven times more likely to report work disability than their nondiabetic siblings (32.4% versus 4.6%). Moreover, the largest impact of disability in the diabetic population appears to be in the most severe forms of disability, including being unable to work.

Disability in persons with diabetes is influenced by a number of demographic and diabetes-related factors. Impairments reported by diabetic persons increase with age for both NIDDM (18-44 years, 45% report activity limitations; 45-64 years, 55%; ≥65 years, 60%) and IDDM persons (cumulative incidence of work limitations at age 30 years, 10%; age 45 years, 48%).

Disability is more common in minority groups (black females, 57.4% report activity limitations; black males, 58.4%; white females, 51.6%; white males, 47.1%). Disability appears to affect persons with NIDDM, particularly those using insulin (63.5% report activity limitations), more than persons with IDDM (42.9% report activity limitations). Presence of the late complications of diabetes appears to be a major determinant for disability.

The consequences of disability in the diabetes population are extensive. Disabled IDDM subjects have lower rates of employment than those not disabled (49% not working versus 12%) and higher rates of absenteeism (13.8 days per year versus 3.0 per year). Reported income levels are also lower for IDDM subjects developing disability. Disabled persons with diabetes use health care services more frequently than those not limited in activity (32.4% were hospitalized in the past year versus 13.2%). The average number of physician visits among persons seeing a physician was 13.9 per year for persons limited in activity, compared with 6.5 visits per year for those not limited. Limitation in personal care activities of daily living (ADLs) are more common among diabetic than nondiabetic individuals (1989 NHIS, NIDDM: 4.9%, IDDM: 8.8%, nondiabetic: 2.3%). Not surprisingly, disabled persons rate their general health status at lower levels than those not disabled. Diabetic persons reporting activity limitations in the 1989 NHIS were 10 times more likely to rate their health as poor (31.7% versus 3.6%) than were persons not limited in activity.

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INTRODUCTION

Disability is a major social, economic, public health, and political issue confronting society today. Estimates of the number of disabled persons in the United States vary greatly, ranging from 27 million to 35

million to 49 million¹⁻³. Disability is associated with an increased likelihood for hospitalization, institutionalization, and loss of economic self-sufficiency and normal role behaviors^{4,5}. In addition, some persons with disabilities face barriers in the work environment and difficulties in gaining access to public facilities⁶. These circumstances, together, greatly di-

minish the quality of life of those affected^{2,4}.

Chronic diseases are a major determinant of disability⁷. Diabetes is a chronic disease in which many individuals can lead normal and productive lives. Other persons, though, face impairments and limitations related to their diabetes that influence their meaningful participation in normal activities of everyday life. A review of the prevalence of disability in the diabetes population and the characteristics of these people is the focus of this chapter.

DEFINITION OF DISABILITY

Unlike most clinical measures associated with diabetes, the definition of disability as it applies to persons with diabetes, as well as persons in the general population, is multidimensional. Disability can be defined quite narrowly or quite broadly. There is currently no standard definition used in the literature.

Very early on, disability was defined solely by the presence of a physical disability, such as the loss of a limb. The work of two individuals, though, moved the discussion beyond physical disabilities and into a broader domain. Both Saad Nagi and Philip Wood described disability in terms of its impact on the individual (physical, medical, anatomical, and emotional), and its impact on lifestyles. These are, in turn, mediated by the environment and family situation in which the person lives.

In the late 1960s and early 1970s, Nagi outlined disability in terms of four closely related views: pathology, impairment, functional limitation, and disability⁸⁻¹⁰. The relationship among these views is shown in

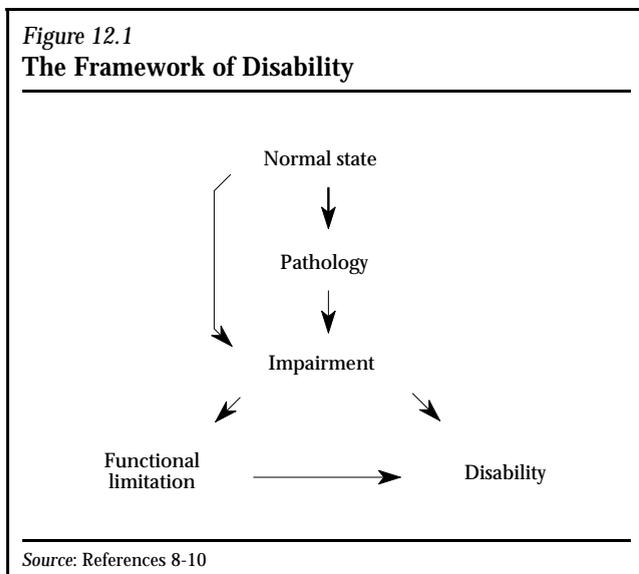


Figure 12.1. Active pathology is defined by Nagi as some type of interference in the normal processes of the organism, such as the onset of disease. This pathology may lead to an impairment (an anatomical, physiological, mental, or emotional loss or abnormality). Impairments, though, may arise independent of a pathology. Impairments may then exert their effects in terms of functional limitations (a limitation in functioning or performance at the individual level, e.g., a problem in seeing, hearing, walking, or reaching), or in terms of a disability (a limitation in performing socially defined roles, e.g., self-care or work).

In 1980, Wood developed a framework for the World Health Organization that identified disability as encompassing impairments, disabilities, and handicaps¹¹. Impairment in this case denoted any loss or abnormality in physiologic or anatomic structure or function. Disability indicated any restriction or inability (resulting from an impairment) to perform an activity in the manner considered normal for that individual. Handicap was defined as any disadvantage (resulting from an impairment or disability) that limits the fulfillment of normal role behavior for the individual.

SPECTRUM OF DISABILITY

As outlined above, the spectrum of disability is wide. Moreover, disability is often distinguished by the interaction between individuals and their environment. Not every impairment results in disability or handicap. Individuals with similar conditions can differ in the severity of their impairment and their ability to meet normal role expectations due to the influence of the environment¹². Some will have family situations that enable them to overcome social barriers. Others will use equipment to overcome physical barriers. The 1990 Americans with Disabilities Act¹³ aspires to reduce some of the access and employment barriers that disabled persons face.

In summary, the impact or severity of disability is variable. The influence may be permanent or temporary. It may affect the ability to work and the ability to enjoy other life activities. It may affect the use of health care services and the patterns of health insurance coverage³. Persons may be limited in self-care activities such as eating, bathing, and dressing, or they may face difficulties in moving around, lifting objects, and walking up and down stairs. Disability may change the income levels of those affected, influence the use of social programs, or prejudice the decisions of individuals living with some uncertainty of what lies in their futures^{3,4}.

Table 12.1
Some Examples of the Disability Framework and Diabetes

Pathology	Impairment	Functional limitation	Disability
Onset of diabetes	Worry over complications		
Hypoglycemia	Diminished judgment	Slow reaction time	No work until blood glucose is raised
Onset of proliferative retinopathy	Diminished vision	Cannot drive at night	Difficult to go out after dark

DIABETES AND DISABILITY

Diabetes is likely to be associated with disability through a number of processes, a few of which are outlined in Table 12.1. For example, a sense of uncertainty about the future is evident in some persons at the onset of the disease and throughout life. The acute complications of diabetes might be characterized as temporary impairments and may be associated with some limitation in physical and social performance. The most common scenario is that impairments, limitations, and disabilities will result from the development and progression of the chronic complications of diabetes.

SOURCES OF DISABILITY DATA

Despite the resourcefulness of the disability frameworks, it has been difficult to incorporate all of the concepts into research and surveys of the population. Most surveys assess disability in one or more of the following terms: a) presence of a condition or diagnosis, b) ability to get around (mobility) or take care of oneself, c) ability to work, and d) eligibility for government disability programs. The federal government has been the primary source of data describing the epidemiology of disability associated with diabetes. Surveys by the National Center for Health Statistics (NHIS), the Census Bureau (Survey of Income and Program Participation, or SIPP), and the Social Security Administration (Disability and Work Survey) have all assessed disability on a regular basis in some form, although each has used different survey instruments.

NATIONAL HEALTH INTERVIEW SURVEY

The National Center for Health Statistics reports on the characteristics of disability in the NHIS, a popula-

tion-based survey that includes questions on disability, among other health issues. The primary measures of disability in the survey are activity limitations due to impairments or health problems and restricted activity days. Activity limitations are categorized into four groups¹⁴: 1) unable to perform major activity, such as going to school, work, housekeeping, or (in the elderly) ADLs; 2) limited ability to perform major activity; 3) limited in activity, but not in major activity; and 4) not limited.

Disability days are also assessed in the noninstitutionalized population. A disability day is defined as a day on which a person has to reduce his/her usual activity because of illness or injury¹⁴. Four types of disability days are defined in the NHIS: 1) bed days, 2) work loss days in the currently employed, 3) school loss days among children, and 4) total restricted activity days. Further disability measures are assessed in subgroups of the population. Limitations in the ability to work are asked of all adults age 18-69 years. Difficulties in the ADLs (e.g., eating, bathing, dressing, shopping, doing housework) are asked of persons reporting activity limitations and the elderly.

Diabetes is determined in the NHIS by asking persons if they have ever been told by a doctor that they have diabetes. For persons reporting activity limitations, the condition that caused it is also queried. In 1989, a supplement on diabetes was included in the NHIS to learn more about diabetes screening, current treatment regimens, diabetes complications, and risk factors for diabetes^{15,16}. The supplement also provided information to determine whether the respondents had IDDM or NIDDM. Subjects with IDDM were defined by age <30 years at onset of diabetes, continuous use of insulin since diagnosis, and having a desirable body weight $\leq 120\%$ of normal. Persons with NIDDM were defined as all other persons with diabetes (who did not have gestational diabetes or report pre-, potential, or borderline diabetes).

SURVEY OF INCOME AND PROGRAM PARTICIPATION

The U.S. Census Bureau reports on the disability status of the population in periodic panels of the annual SIPP. The SIPP assesses the economic situation of households and persons in the United States, providing information useful for evaluation of present and future government programs¹⁷. Various types of disability measures have been assessed in the panels to the SIPP. These include:

- Limitations in sensory or physical functioning

- Difficulty with ADLs
- Presence of specific mental, cognitive, or developmental conditions
- Presence of conditions that limit work, housework, or school activity
- Receiving disability-related benefits
- Use of mechanical aids

- Occupational disability—able to work regularly, but not full time, or at the same kind of job
- Secondary work limitations—able to work regularly, full time at the same job as before disability, but limited in kind and/or amount of work

The contribution of specific health conditions to disability status has not been studied in much detail in the SIPP. The few questions in this area have focused on identifying the specific condition(s) that caused work disability, physical limitation, or limitation in the ADLs or Instrumental Activities of Daily Living (IADLs)^{3,17}. Diabetes was included as one of 30 different conditions that respondents could identify as the cause of the respective disability.

SOCIAL SECURITY DISABILITY INSURANCE

The Social Security Administration (SSA) reports from time to time on the characteristics of people awarded Social Security disability insurance benefits. Statistics on the demographic, socioeconomic, and medical characteristics of disabled workers are usually presented in their reports^{18,19}. The definition of disability applied in the Old Age, Survivors, and Disability Insurance (OASDI) program is quite restrictive. Persons must be unable to participate in gainful activity due to a medically determinable physical or mental impairment. This impairment must exist for 5 months before the person can qualify for a disabled-worker benefit. Furthermore, the impairment should be expected to last for at least 12 months or lead to death²⁰. Consequently, this measure of disability is likely to reflect severe cases. Disabled individuals with diabetes are reported in SSA statistics when diabetes is the primary cause of disability.

SURVEY OF WORK AND DISABILITY

In 1972 and 1978, the SSA conducted the Survey of Work and Disability, a population-based survey on the characteristics of occupational disability. In these surveys, occupational disability was defined as any limitation in the kind and/or amount of work that a person can do as a result of a chronic health condition or impairment²¹. The categories of work disability included:

- Severe disability—unable to work regularly or at all

LIMITATIONS OF U.S. GOVERNMENT DATA

In general, the prevalence of disability is presented adequately in the surveys outlined above. Information is available on the number of diabetic persons disabled, the type of disability present, and the number of work-days lost. As will be noted below, each survey has also shown the impact of disability to be more profound in the diabetic population than in the nondiabetic population. Some limitations, though, are intrinsic to these surveys. For example, the NHIS and SIPP represent disability in the noninstitutionalized population. More severe cases of disability that require institutionalization are not included in these two surveys (see Chapter 28). There also is little assessment of the incidence of disability and no longitudinal followup of the population to examine changes or progression in disability. As defined in the frameworks above, disability is a dynamic process. Questions also exist about the adequacy of ascertainment of the diabetic population and the ability to distinguish NIDDM from IDDM. Because IDDM occurs infrequently in the population, the 1989 NHIS had only a small sample of IDDM persons (n=121 total, 101 age <45 years)¹⁵.

COMMUNITY-BASED EPIDEMIOLOGIC STUDIES

Some information on disability is available from surveys of specific populations of the diabetes community, such as Mexican Americans and persons with IDDM. These data provide further examination of the prevalence and risk factors for disability. Again, the specific measures of disability differ among the studies.

INDUSTRIAL STUDIES

Reports based on industrial populations have described the disability characteristics of persons with diabetes. Industry's concern over diabetes-related disability centers around the monetary issues involved with the subsequent loss of production, high rates of absenteeism, and higher insurance premiums. In the surveys conducted in this setting, employment records of diabetic individuals were compared with em-

ployment records of those in the work force without diabetes. Limitations in these studies include inadequate identification of diabetic employees, inadequate description of disability in females with diabetes, and lack of matched control groups.

PREVALENCE OF DISABILITY

Disability affects large numbers of persons with diabetes in the United States. Estimates range from 20%-50% of the diabetic population. Persons with diabetes are two to three times more likely to report disability than their counterparts in the general population. The greatest degree of difference appears for the most serious forms of disability. Diabetes is often accompanied by another condition leading to disability.

Estimates of the prevalence of disability associated with diabetes are available from a number of sources. There is some discrepancy among studies on the extent of disability in the diabetes population. This is due to the diversity of disability measures used. Instruments assessing relatively severe forms of disability report lower prevalence rates than those assessing relatively mild forms. Figure 12.2 outlines the scale of disability used in previous studies of diabetes populations. By considering the intensity of the measure, the impact of disability in diabetes can be placed in a better perspective.

NATIONAL HEALTH INTERVIEW SURVEY

The most comprehensive examination of disability indicators is contained in the NHIS. Chronic diseases,

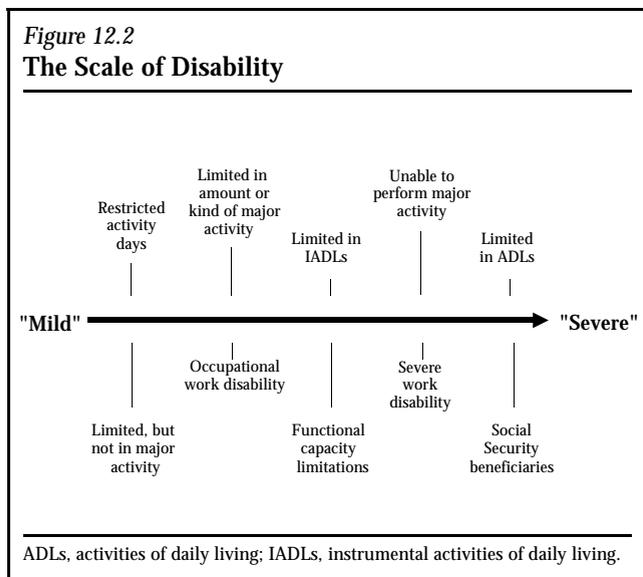
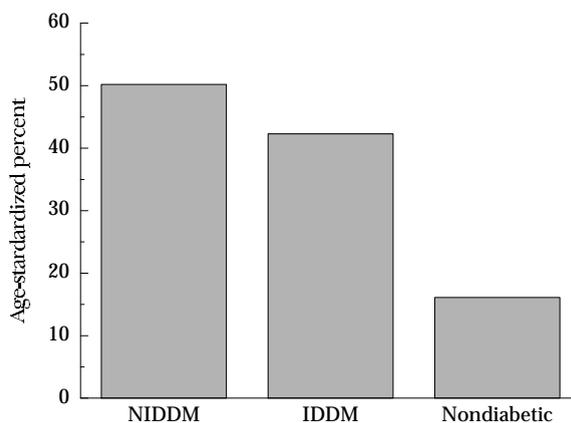


Figure 12.3
Age-Standardized Percent of Persons Age ≥ 18 Years Reporting Activity Limitations, U.S., 1989



Source: 1989 National Health Interview Survey

including diabetes, are strongly linked with reported activity limitations in the NHIS². In 1983-85, diabetes was the 11th most common condition cited as the main cause for activity limitation in the United States, accounting for 2.7% of all reported cases². When considered as any contributing cause of activity limitation, diabetes was the sixth most frequent condition cited, explaining 6.5% of all cases.

In 1989, the NHIS supplement on diabetes allowed for a more detailed examination of disability related to diabetes. About half of all persons with diabetes reported an activity limitation (of any type) related to an impairment or health problem (Figure 12.3). Activity limitations were two to three times higher for persons with NIDDM and IDDM compared with persons without diabetes (Appendix 12.1).

The greatest degree of difference in disability between people with diabetes and the nondiabetic population appeared for the most serious form of activity limitation, being unable to perform their major activity (Table 12.2). Significant percentages of the diabetic population reported being unable to carry on their major activity (NIDDM, 20.6%; IDDM, 13.9%; Appendix 12.2). A similar proportion of people with diabetes reported being limited in the amount or kind of major activity they could undertake.

A limitation in major activity was defined as 1) having difficulty in working at a job or business, in house-keeping, or in going to school (for persons age 18-69 years), or 2) having difficulty in the independent performance of ADLs (for persons age ≥ 70 years). Figure 12.4 shows the type of major activity reported

Table 12.2
Age-Standardized Percent of Persons Age ≥18 Years, by Type of Activity Limitation Reported, U.S., 1989

	NIDDM	IDDM	Nondiabetic population
Unable to carry on major activity	19.4	15.1	4.5
Limited in the kind or amount of major activity	19.0	18.3	6.1
Limited, but not in major activity	11.8	8.9	5.4
Not limited	49.8	57.7	83.9

Data are age-standardized to the 1989 National Health Interview Survey sample population using three age groups. The data representing IDDM subjects are based on small sample sizes.

Source: 1989 National Health Interview Survey

by diabetic and nondiabetic subjects in the NHIS. A smaller proportion of persons with diabetes, particularly those with NIDDM, reported working at a job or business. Perhaps the most important life activity for an adult is being able to work at a job or business. In 1990, nearly 42% of persons age 18-69 years with diabetes reported being unable to work or being limited in the kind or amount of work activity they could do²². About 28% of the population reported being unable to work at all.

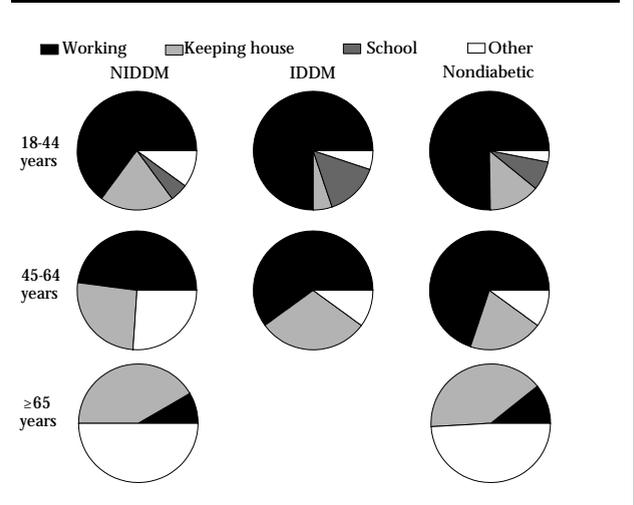
Another measure of disability in the NHIS is the survey of restricted activity days over a 2-week period. Restricted activity days are a broader measure of disability because they consider reductions in usual activity related to long-term or short-term conditions¹⁴. The discussion above of activity limitations focused on long-term reductions in capacity only. In 1989, about one-fifth of the diabetes population reported at least one restricted activity day in the past 2 weeks (Table 12.3, Appendix 12.3). This proportion was twice that reported by the nondiabetic population.

Table 12.3
Age-Standardized Percent of Persons Age ≥18 Years Reporting Any Restricted Activity Days in the Previous 2 Weeks, U.S., 1989

	NIDDM	IDDM	Nondiabetic
Any restricted activity days	22.4	21.3	10.3
Bed days	14.2	14.7	5.7
Work-loss days (among the employed)	11.2	11.4	6.1
Other restricted activity days	11.5	10.7	5.2

Source: 1989 National Health Interview Survey

Figure 12.4
Type of Major Activity Reported by 1989 NHIS Participants, by Diabetes Status and Age

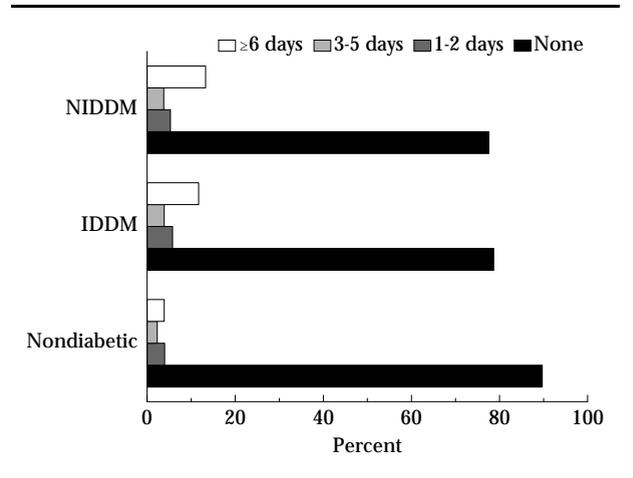


NHIS, National Health Interview Survey.

Source: 1989 National Health Interview Survey

The distribution of restricted activity days for the diabetic and nondiabetic populations in the 1989 NHIS is shown in Figure 12.5. While most persons with diabetes did not report any restrictions in their usual activity in the previous 2 weeks, those who did described lengthy cutbacks in activity. Thirteen percent of the persons with NIDDM and 11% of those with IDDM reported ≥6 days of restricted activity in the preceding 14 days. This was markedly higher than the 3.9% of the nondiabetic population indicating a similar degree of impairment.

Figure 12.5
Percent Distribution of Restricted Activity Days, by Diabetes Status, U.S., 1989



Source: 1989 National Health Interview Survey

A Supplement on Aging was included in the 1984 NHIS and was used, in part, to assess disability in basic life activities among the U.S. population age ≥ 65 years. These basic operations include ADLs and IADLs. The ADL scale examines the level of self-sufficiency of the person in basic self-care activities (bathing, eating, dressing, transferring from a bed to a chair, using the toilet) and mobility²³. The IADL scale examines further activities important for living independently (cooking, shopping, managing money, using the phone, using transportation, housekeeping)²⁴.

In 1984, about one-third (33.5%) of the diabetes population age ≥ 65 years was estimated to be dependent in at least one ADL or IADL²⁵. Extrapolated to the 1992 population with diagnosed diabetes²⁶, this represents ~1.1 million persons with diabetes who were dependent. Nearly one-quarter (24.4%) were dependent in at least one ADL, and 7.3% were dependent in ≥ 3 ADLs. Dependence in this study was defined as having difficulty in performing an activity or being unable to perform an activity due to a health or physical problem, without the help of another person or assistive device²⁵.

SURVEY OF INCOME AND PROGRAM PARTICIPATION

Two panels of the SIPP, in 1984-85 and 1991-92, have addressed disability issues. With an emphasis on gathering data on disability and the use of government programs, the SIPP has not focused to a large extent on the role of chronic conditions in disability. The 1984-85 panel, though, did examine the conditions mainly responsible for work disability and the need for personal assistance.

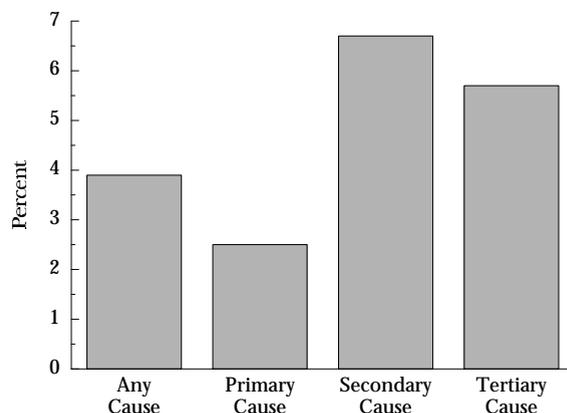
Diabetes was the seventh most frequently cited condition listed as being mainly responsible for work disability¹⁷. In 1984-85, an estimated 806,000 persons with diabetes had some type of work disability (equivalent to 3.4% of all persons disabled in work activity). Of this figure, 482,000 were entirely unable to work and 79,000 were able to work, but not in full-time employment. About 245,000 persons with diabetes were estimated to have a disability but were still able to work full-time. These findings are in general agreement with the results of other surveys regarding work disability. Severe work disability, reflected in the inability to work at all, accounts for the largest proportion of all work-disabled individuals. With respect to the need for personal assistance, an estimated 116,000 persons with diabetes needed some help in "getting around," while 169,000 persons needed help with housework or meal preparation.

Information from the 1991-92 panel lists the conditions reported as being the cause of limitations in functional activities, ADLs, or IADLs. Diabetes was, again, the seventh most frequently cited condition mentioned as a cause of disability, representing 3.9% of all responses (Figure 12.6). Diabetes was cited more often as a secondary or tertiary cause of limitation in normal activities than as a primary cause of incapacity.

SOCIAL SECURITY DISABILITY INSURANCE

The SSA manages the largest government program for people with disabilities. The Social Security Disability Insurance (SSDI) program is directed toward income support for persons no longer able to work. Few reports have used SSDI data to examine disability issues in persons with diabetes. Measuring the impact of diabetes-related disability from this source is difficult in several respects. First, applicants for benefits have to demonstrate that their impairment precludes their participation in normal activity and will continue to do so in the long term. Thus, only severe cases of disability are identified from this source. Second, information is available only on the number of disability claim allowances related to diabetes. These represent new judgments for benefits or new judgments that an applicant has established a period of disability. No information is available on the total number of diabetes-related beneficiaries in the system. Third, the eligibility criteria for benefits have changed considerably

Figure 12.6
Diabetes as a Reported Cause of Limitation in Functional Activity, ADL, or IADL, U.S., 1991-92



ADL, activities of daily living; IADL, instrumental activities of daily living.

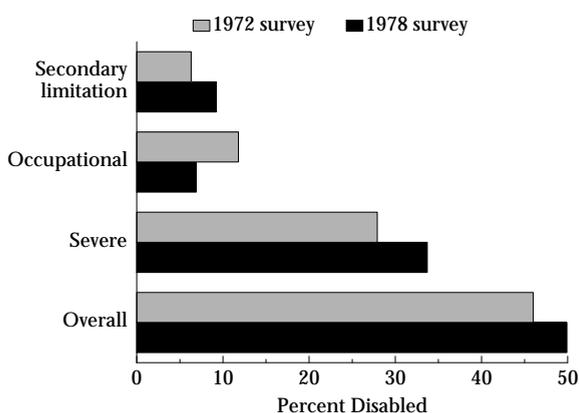
Source: 1991-92 Survey of Income and Program Participation, Social Security Administration

over time. Fourth, the SSA has only considered the impact of diabetes as a primary cause of disability. As demonstrated earlier, diabetes is a significant factor as a second or third condition contributing to disability. The latest available data show that 8,250 persons with diabetes were granted disability claims allowances in 1984¹⁹. This number represents 2.3% of all allowances given that year.

SURVEY OF WORK AND DISABILITY

More appropriate measures of disability related to diabetes can be found in the Survey of Work and Disability conducted by the SSA. While this specific survey is no longer being administered, the 1972 and 1978 versions indicated that 45%-50% of diabetic people were limited in their work activities in one form or another (Figure 12.7)^{27,28}. This amount of disability was about three times greater than that in the general population, where 14%-17% were work-disabled. The largest degree of difference in disability between the diabetic and general populations was found for the most severe form of work disability, being unable to work at all. Greater percentages of the diabetic subjects (28%-34%) were unable to work (severe disability) compared with the general population (7%-8%). Higher burdens were also noted for the lesser forms of work disability (occupational disability—being able to work, but not full time at the same job; secondary work limitations—able to work the same job, but limited in what the person can do).

Figure 12.7
Percent of Persons with Diabetes Age 20-64 Years Reporting Work Disability, by Type of Limitation, U.S., 1972, 1978



Source: 1972 and 1978 Surveys of Work and Disability, Social Security Administration, References 27 and 28

NATIONAL NURSING HOME SURVEY

While the 1984 NHIS Supplement on Aging considered disability in the noninstitutionalized aged population, many older persons with significant disabilities are living in long-term care institutions. The 1985 National Nursing Home Survey sampled nursing homes and their residents nationwide. Data from this survey and the 1984 Supplement on Aging suggest that 19.5% of all functionally dependent persons with diabetes (dependence in at least one ADL or IADL) reside in nursing homes²⁵. In 1985, an estimated 165,000 diabetic persons age ≥65 years with dependence in at least one ADL or IADL were resident in nursing homes²⁵. Nearly 78% of these persons were dependent in ≥3 ADLs. Chapter 28 presents more information on disability in institutionalized people with diabetes.

COMMUNITY-BASED EPIDEMIOLOGIC STUDIES

Measures of disability have been assessed in separate and distinct epidemiologic surveys of persons with diabetes in U.S. communities. Among them, the Pittsburgh Epidemiology of Diabetes Complications (EDC) Study has examined disability issues since 1986. The EDC study is an ongoing investigation of factors related to diabetes complications in persons with IDDM. The study population is based on all childhood-onset diabetes patients seen at the Children's Hospital in Pittsburgh in 1950-80 who are living in the Pittsburgh, PA region. The mean age of the 658 participants at the baseline examination was 28 years. The mean duration of IDDM was 20 years^{29,30}.

Nearly one person in five in this relatively young cohort reported diabetes-related limitations in the type or amount of work they could do at home, at school, or on the job (Table 12.4). Furthermore, of the 22% reporting limitations at the 4-year followup, one-

Table 12.4
Percent of IDDM Persons Limited in Work, Home, or School Activities Due to Diabetes-Related Problems, Pittsburgh EDC Study

	Sample size (no.)	Percent limited
Baseline survey (1986-88)	625	17.1
2-year followup (1988-90)	481	18.9
4-year followup (1990-92)	430	21.6

EDC, Epidemiology of Diabetes Complications.

Source: Pittsburgh Epidemiology of Diabetes Complications Study

third had difficulties in at least one ADL, 57% had difficulties in at least one IADL, and 75% reported difficulties in functional capacity (i.e., walking, standing for long periods, reaching, lifting, grasping, etc.).

The prospective nature of the EDC study highlights the dynamic nature of disability. Figure 12.8 charts the development (incidence) of diabetes-related limitations from the time of the baseline examination. Among those persons reporting no problems in their work activity at baseline, 5% identified a diabetes-related limitation 2 years later and 11% did so at the 4-year follow-up examination. Some persons indicated an improvement in their disability status over time: among participants reporting disabilities at baseline, 14% had no trouble at the 2-year followup and 22% had no diabetes-related limitations at the 4-year examination.

Another case-control investigation focused on an older cohort (mean age 33 years) of the CHP IDDM Registry. This study surveyed the employment experiences of 158 adults with IDDM and their nondiabetic brothers and sisters³¹. IDDM subjects were seven times more likely to report being disabled in their work abilities than their age- and sex-matched siblings (Table 12.5). A sizable percentage were unable to work at all (12.6%).

ATTRIBUTES RELATED TO DISABILITY

Disability in persons with diabetes is influenced by a number of factors, the strongest of which is the presence of the late complications of diabetes. The preva-

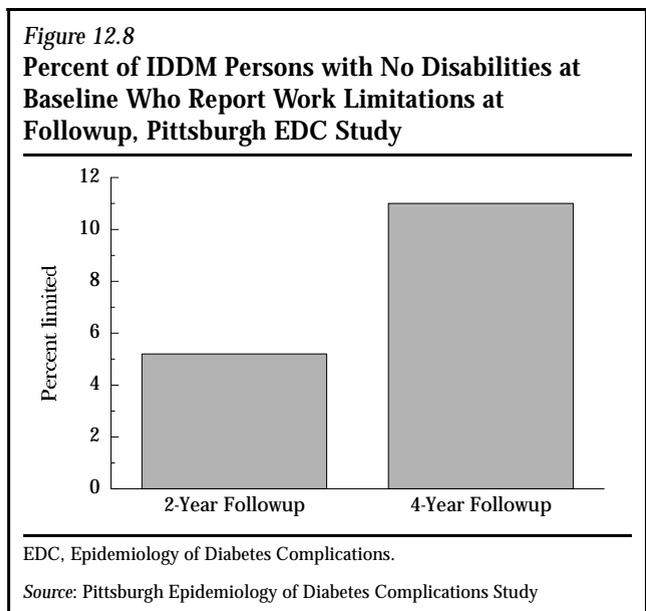


Table 12.5
Percent of Persons Disabled in Work Activity, Children's Hospital of Pittsburgh IDDM Registry, 1985

	IDDM subjects	Nondiabetic siblings
Any work disability	32.4	4.6
Severe disability	12.6	0.0
Occupational disability	9.9	0.6
Secondary work limitations	9.9	4.0

Source: Reference 31

lence of impairments increases steadily with age, but disability still affects large numbers of young people with diabetes. Disability is more common in women and minority ethnic groups, and it appears to affect persons with NIDDM more frequently than those with IDDM. In IDDM, disability increases with longer duration of diabetes.

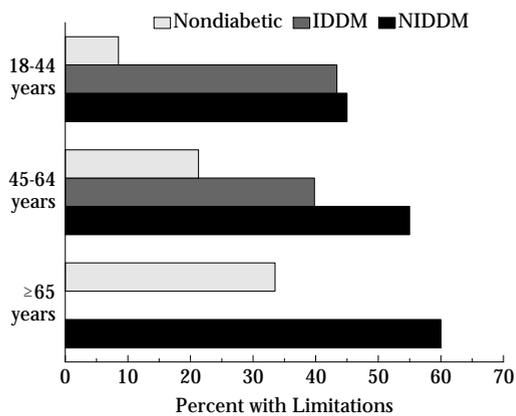
DEMOGRAPHIC FACTORS

The attributes of disability vary enormously from individual to individual. Two persons with the same relative degree of health may respond quite differently when queried about their ability to carry on normal activities. One individual may have a supportive environment, while another may not. A number of elements are correlated with the evolution of disability in persons with diabetes. While it has been difficult to quantify the importance of all the variables that influence disability, there is a great deal of information on the relationship of disability with selected demographic factors (age, gender, race, income, education, etc.).

The characteristics of disability in the diabetes community are, in general, similar to those seen in the general population. Activity limitations reported in the 1989 NHIS increased with advancing age for persons with NIDDM (Figure 12.9). Data from the 4-year follow-up examination in the EDC study indicate a similar tendency for persons with IDDM (Figure 12.10). Data from the 1989 NHIS (Appendix 12.1) and the 1972 Survey of Work and Disability (Table 12.6) suggest that the largest degree of difference in reported disability between the diabetic and nondiabetic populations is found at younger ages.

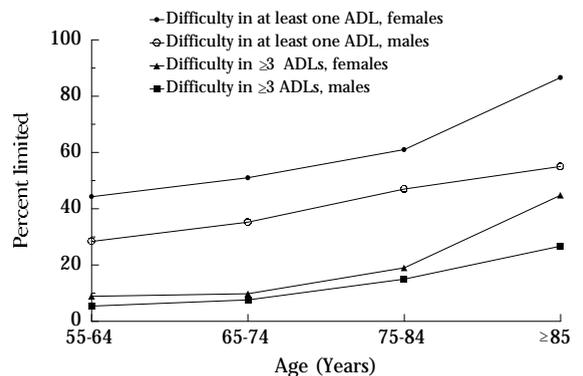
Increasing rates of disability occur with advancing age in older diabetic Americans. Substantial percentages of the diabetes population age ≥55 years reported difficulties in at least one ADL in the 1984-85 Supple-

Figure 12.9
Percent of Persons Reporting Activity Limitations, by Age Group, U.S., 1989



Source: 1989 National Health Interview Survey

Figure 12.11
Percent of Diabetic Population with Difficulties in ADLs, by Age and Gender, U.S., 1984



ADLs, activities of daily living; NHIS National Health Interview Survey.

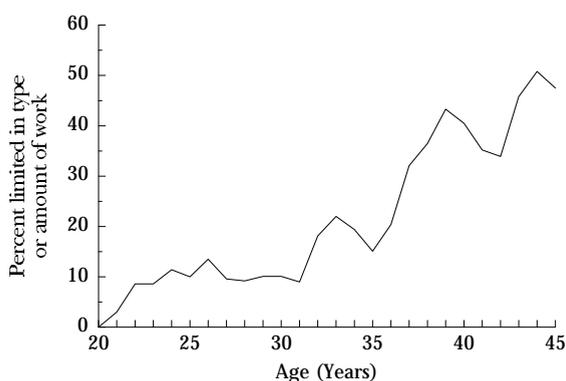
Source: Supplement of Aging, 1984 National Health Interview Survey; Reference 32

ment on Aging (Figure 12.11)³². More than one woman in every two with diabetes indicated a dependency of some type in these self-care activities.

As a group, women with diabetes have higher rates of disability than men; this pattern is also found in the nondiabetic population (Table 12.7). While disability is more frequent in females, from most indications the gender difference is not significant for the diabetes population. Moreover, the excess disability in females may only exist at an older age. Activity limitations in the 1989 NHIS were slightly more frequent at age 18-44 years in diabetic men before becoming more

frequent at age ≥45 years in diabetic women (Figure 12.12). The Framingham Heart Study examined the contributory role of diabetes in the development of

Figure 12.10
Percent of IDDM Subjects Reporting Being Limited in Type or Amount of Work Activity, by Age, Pittsburgh EDC Study, 1990-92



EDC, Epidemiology of Diabetes Complications; Data are 3-year moving average

Source: Pittsburgh Epidemiology of Diabetes Complications Study

Table 12.6
Percent of Persons Reporting Work Disability, by Age, 1972

Age (years)	Diabetic (%)	Nondiabetic (%)
<45	34.0	8.4
45-54	42.3	19.0
55-64	57.4	28.8

Source: 1972 Survey of Work and Disability, Social Security Administration

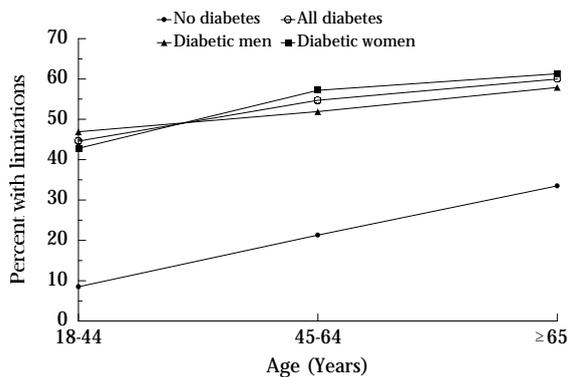
Table 12.7
Percent of Persons Reporting Disability, by Gender

Data source	Disability measure	Diabetic population		Nondiabetic population	
		Men	Women	Men	Women
NHIS, 1989	Activity limitations	53.5	57.1	14.9	16.1
Survey of Work and Disability, 1972	Work disability	44.7	47.3	13.6	15.0
	Severe disability	23.1	32.6	5.7	8.3
EDC survey, 1990-92	Work limitations	18.0	25.0		
CHP IDDM Registry, 1985	Work disability	32.1	32.8	4.8	4.5
	Severe disability	15.5	9.0	0.0	0.0

NHIS, National Health Interview Survey; EDC, Pittsburgh Epidemiology of Diabetes Complications Study; CHP Children's Hospital of Pittsburgh.

Source: Sources are listed within the table

Figure 12.12
Percent of Persons with Diabetes Reporting Activity Limitations, by Age and Gender, U.S., 1989

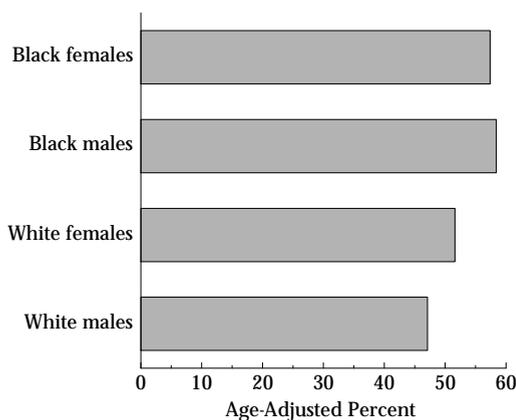


Source: 1989 National Health Interview Survey

physical disability³³. In a cohort of 2,021 persons free of cardiovascular disease, diabetes was associated with measures of physical disability in women, primarily those age >75 years, but not in men.

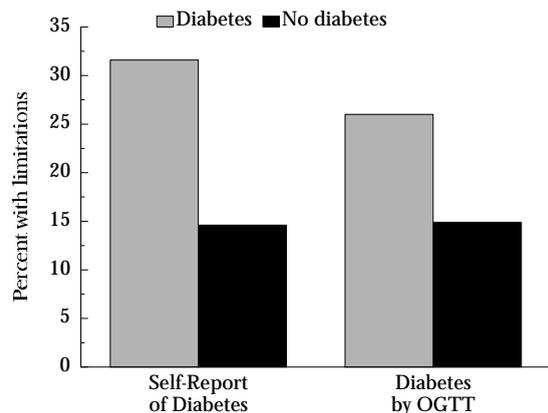
Analyses considering racial attributes find higher disability rates in African Americans. Figure 12.13 shows information from the 1989 NHIS. Both black men and black women have a higher prevalence of activity limitations than whites²². Similarly, the prevalence of work disability was higher in African Americans than in whites (55.2% versus 44.3%) in the 1972 Survey of Work and Disability²⁷.

Figure 12.13
Age-Adjusted Prevalence of Activity Limitations Related to Chronic Conditions in Diabetic Subjects, by Race and Sex, U.S., 1989



Source: 1989 National Health Interview Survey

Figure 12.14
Prevalence of Activity Limitations in Mexican Americans with Diabetes, by Medical History and OGTT, HHANES, 1982-84



OGTT, oral glucose tolerance test; HHANES, Hispanic Health and Nutrition Examination Survey.

Source: 1982-84 Hispanic Health and Nutrition Examination Survey; Reference 34

Evaluation of other ethnic groups in national surveys is difficult because of small sample sizes. However, the 1982-84 Hispanic Health and Nutrition Examination Survey (HHANES) focused on U.S. Hispanic populations. Based on this survey³⁴, activity limitations were nearly two times more common in Mexican Americans with diabetes than in Mexican Americans without diabetes (Figure 12.14).

Significant associations between disability and education or income were found in the 1989 NHIS (Table 12.8). Activity limitations were highest among per-

Table 12.8
Age-Standardized Percent of Persons Age ≥18 Years Reporting Activity Limitations, by Education and Income, U.S., 1989

	NIDDM population	Nondiabetic population
Education (completed years)		
<9	67.7	22.7
9-12	50.3	16.3
≥13	40.7	13.1
Income		
<\$10,000	71.1	30.6
\$10,000-19,999	54.6	20.1
\$20,000-34,999	46.0	15.5
\$35,000-49,999	24.5	11.8
≥\$50,000	33.0	9.3

Data are age-standardized to the 1989 National Health Interview Survey sample population using three age groups.

Source: 1989 National Health Interview Survey

Table 12.9
Percent of Persons Reporting Activity Limitations, by Type of Diabetes Treatment, U.S., 1989

Age (years)	NIDDM, using insulin	NIDDM, using oral agents	NIDDM, using diet alone	IDDM
≥18	63.5	52.4	48.3	42.9
18-44	52.9	46.5	26.1	43.4
45-64	62.3	47.6	58.9	39.8
≥65	68.1	56.9	48.8	

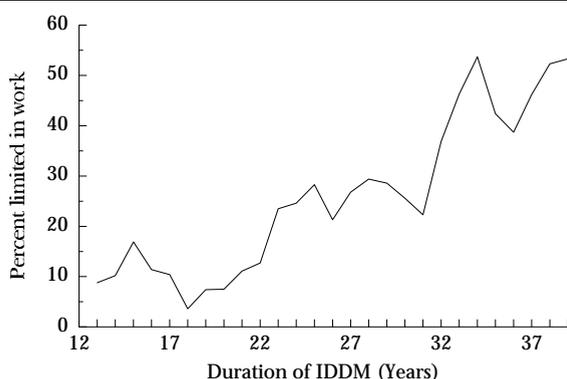
Source: 1989 National Health Interview Survey

sons with the fewest years of education and the lowest income levels, even after adjusting for age. Similar correlations were noted for persons with IDDM in the EDC study. While income may be suppressed by disability, the association with lower levels of education indicates a strong tendency for higher rates of disability in lower socioeconomic groups.

DIABETES-RELATED FACTORS

Table 12.9 presents the frequency of activity limitations among respondents to the 1989 NHIS diabetes supplement by type of treatment. Individuals with NIDDM who were using insulin reported more limitations in normal activities than persons using oral agents or diet alone to control their diabetes. Subjects with NIDDM appear to have higher rates of limitation than persons with IDDM, although the sample size of respondents with IDDM was small.

Figure 12.15
Percent of IDDM Persons Reporting Work Limitations, by Duration of Diabetes, Pittsburgh EDC Study, 1990-92



EDC, Epidemiology of Diabetes Complications. Data are 3-year moving averages. Limitations include those in the type or amount of work that can be performed.

Source: Pittsburgh Epidemiology of Diabetes Complications Study

Table 12.10
Prevalence of Disability in IDDM Persons with Diabetes-Related Complications, Pittsburgh Epidemiology of Diabetes Complications Study, 1990-92

Complication	Prevalence of disability (%)
Retinopathy	44.4
Nephropathy (overt)	38.0
Coronary heart disease	54.2
Definite peripheral vascular disease	47.2
Definite neuropathy	43.6
Hypertension	43.6
All persons with IDDM	21.6

Source: Pittsburgh Epidemiology of Diabetes Complications Study

Data from the 4-year follow-up examination in the EDC study indicate that the frequency of disability increases with longer duration of diabetes in patients with IDDM (Figure 12.15).

The strongest factor associated with disability appears to be the presence of the late complications of diabetes. Persons with complications are more likely to be impaired in their normal activities than are those without the chronic complications of diabetes. In the EDC study, 35.7% of subjects with complications were limited in the type or amount of work they could perform. Only 3.5% of subjects without complications were so limited. There was no single condition or complication that accounted for this finding. Each type of complication was significantly associated with disability (Table 12.10). Higher rates of activity limitations were also observed among respondents with NIDDM and complications in the 1989 NHIS (Table 12.11).

Table 12.11
Limitation in Activity of NIDDM Persons with Diabetes-Related Complications, Age ≥18 Years, U.S., 1989

Complication	Limited in activity (%)
Retinopathy	66.3
Laser treatment for retinopathy	74.1
Glaucoma	73.7
Cataracts	64.9
Angina or any heart trouble	76.8
Stroke	56.7
Kidney disease or proteinuria	73.5
Amputation	81.6
Sensory neuropathy	73.8
Sores on feet that don't heal	72.3
All persons with NIDDM	56.3

Source: 1989 National Health Interview Survey

TRENDS OVER TIME IN DISABILITY

The evidence regarding trends in the prevalence of disability among persons with diabetes is varied. Depending on the disability measure applied, reports have indicated increasing, decreasing, or constant prevalence. When changes exist, they have been small.

Interpreting changes in the prevalence of disability related to diabetes over time is difficult because of the multiple definitions of disability in the literature. Moreover, assessment strategies have changed over time, even within similar survey instruments. Table 12.12 outlines the frequency of activity limitations among persons with diabetes in the NHIS by year^{28,35}. Direct comparisons between the years are complicated because of differences and changes in the assessment of activity limitations. Despite variation among the surveys, it appears that activity limitations among persons with diabetes may have remained relatively stable over time.

Better information, from a comparison perspective, is available on work limitations as assessed in the NHIS (Figure 12.16)²². Over the 8-year period of 1983-90, self-reported work limitations changed only slightly, from 43.9% to 41.9%. A more notable decline was found for white females and all African Americans. White males, though, showed an increase in work limitations during 1983-90.

Disability allowances in the Social Security program due to diabetes have increased over time (Figure 12.17)³⁶. The number of persons with diabetes, however, has also increased. Furthermore, there is evidence to suggest that the changes in allowances awarded over time for all persons have been due, in

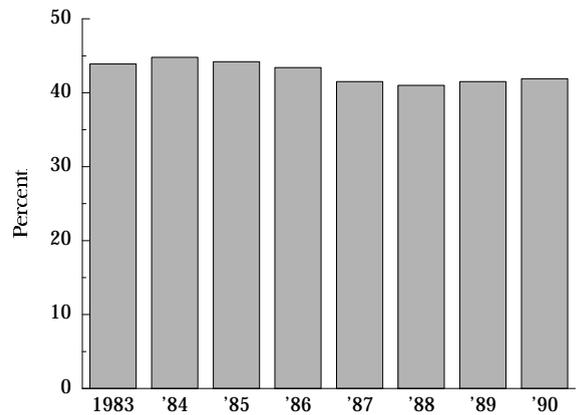
Table 12.12
Trends in the Percent of Diabetic Adults Reporting Activity Limitations, U.S., 1964-89

Age and sex	1964	1979-81	1989
Age (years)			
≥20	54.2	56.5	55.6
20-44	31.9	36.1	48.3*
45-64	46.4	55.3	54.7
≥65	70.6	65.6	60.0
Males	50.9	55.0	53.6
Females	56.6	57.6	57.1

*The youngest age group in the 1989 data is age 18-44 years.

Source: Data are from the National Health Interview Surveys: 1964, Reference 35; 1979-81, Reference 28; 1989, unpublished data from the 1989 Diabetes Supplement

Figure 12.16
Trends in Work Limitations Reported by Persons with Diabetes, U.S., 1983-90



Data are 3-year moving averages.

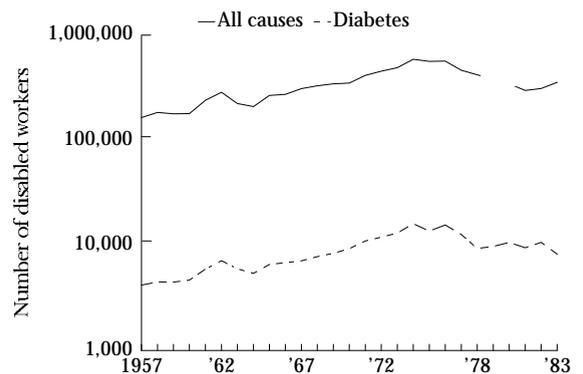
Source: 1983-90 National Health Interview Surveys; Reference 22

part, to changes in the eligibility criteria for the applicants³⁷.

DISABILITY AND EVERYDAY LIFE

Disability affects the lives of persons with diabetes in many different ways. A lower proportion of disabled persons with IDDM are in the work force; those who are employed have higher absenteeism rates than workers without disabilities. Health care use is increased among disabled people, with the number of physician contacts being twice those of people with-

Figure 12.17
Social Security Disability Allowances, by Year and Diabetes Status



Source: Reference 36

out disabilities. Persons developing disability often experience decreases in income levels and greater dependency in basic life activities. These factors and others likely contribute to the lower perceptions of health among disabled persons.

The impact of disability in the diabetes population is wide ranging. Thus, studies that only consider the prevalence of disability seriously undervalue the effect that disability has on the lives of those affected. Disability influences economic, sociologic, and psychologic parameters, among other areas. Significant proportions of disabled persons, for example, are no longer working, particularly those with severe disability²¹. Income differences, largely related to the loss of earnings with the loss of a job, exist between disabled and nondisabled people⁵. These findings and others have led to the view that disabled people live in an atmosphere of "disadvantage"⁴.

The burdens of disability, though, differ by the culture, education, family, and environment in which the person lives. Changes in the public's perception of disability, such as the elimination of bias in job hiring, can increase opportunities for disabled people⁷. Changes in the physical environment, such as the availability of access ramps, can increase the mobility of disabled people.

UNEMPLOYMENT

If the impact of disability on persons with diabetes is similar to that in the general population, then disability

Table 12.13
Self-Reported Employment Status in the Past 2 Weeks by Age and Diabetes Status, U.S., 1989

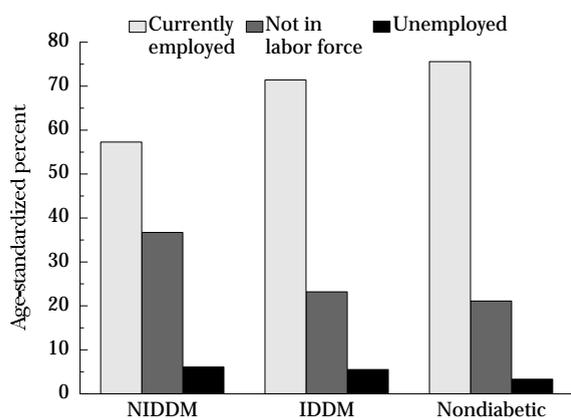
Employment status and age (years)	NIDDM	IDDM	Nondiabetic
Currently employed			
18-44	62.0	79.1	79.3
45-64	47.0	54.7	67.7
Unemployed			
18-44	8.1	5.8	3.8
45-64	1.7	4.7	2.3
Not in the labor force			
18-44	29.9	15.0	16.9
45-64	51.3	40.6	30.0

Source: 1989 National Health Interview Survey

ity will affect the employability of individuals significantly. Information from the 1989 NHIS shows that a lower proportion of diabetic than nondiabetic persons are currently employed, even after adjusting for age (Figure 12.18). Most of this disparity is due to the large number of subjects who are not in the labor force as opposed to being unemployed, particularly for NIDDM (Table 12.13). The influence of disability on this finding, though, is not clear.

More direct information is available from the studies of the CHP IDDM Registry, which found that disabled persons with IDDM were more likely to be not working than those who were not disabled (Figure 12.19). Data from both the 4-year followup of the EDC study

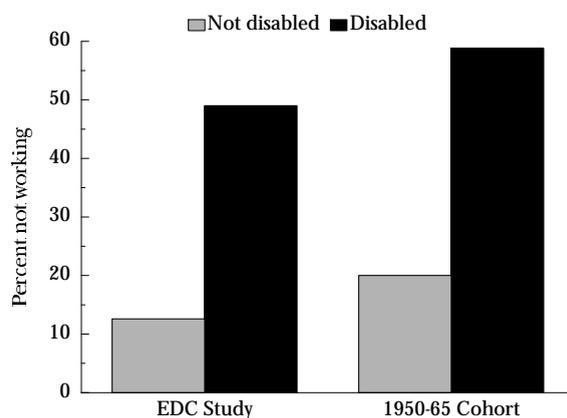
Figure 12.18
Employment Status in the Past 2 Weeks, by Diabetes Status, U.S., 1989



Data are age-standardized for persons age 18-64 years.

Source: 1989 National Health Interview Survey

Figure 12.19
Percent of IDDM Population Not Working, by Disability Status, Children's Hospital of Pittsburgh IDDM Registry, 1985 and 1990-92



EDC, Pittsburgh Epidemiology of Diabetes Complications.

Source: Pittsburgh Epidemiology of Diabetes Complications Study; Reference 31

and a 1985 study of the IDDM cohort diagnosed in 1950-65³¹ indicate that about half of the disabled respondents were not working. This figure was two to three times greater than that observed among subjects without disability.

ABSENTEEISM

For some time now, there has been concern among employers that diabetic employees may have high rates of absenteeism. In the 1950s, concern about diabetes and its implications for loss of productivity and higher insurance premiums led to an examination of disability in the working diabetic population at several industrial sites. The general results of these studies of absenteeism are presented in Table 12.14³⁸⁻⁴⁴.

The findings of the surveys were variable and showed favorable, normal, or unfavorable experiences for the diabetic groups. Most found higher rates of absenteeism for the diabetic employees. There are several methodological shortcomings in these surveys, however, that limit extrapolation of the findings to the general diabetic population. These include the means of identifying employees with diabetes and the inadequate matching with controls.

Absenteeism associated with diabetes has also been assessed in the 1989 NHIS. Absenteeism, measured as the number of work-loss days in the previous 2 weeks, was notably higher among both NIDDM and IDDM respondents, compared with the experience of the nondiabetic population (Appendix 12.3). In the CHP

IDDM Registry, however, no difference in absenteeism was found between working IDDM persons and their working nondiabetic siblings³¹.

While the debate continues regarding the importance of absenteeism in persons with diabetes, one solid conclusion arising from these studies is that significant rates of absenteeism are limited to a small subset of the diabetic population. Most diabetic employees appear to have normal work attendance records. In addition, there is the suggestion that many of the individuals with high rates of absenteeism may be disabled. Data from the 1979-81 NHIS indicate a higher number of work-loss days among diabetic workers with activity limitations than among those without activity limitations (17.5 days per year versus 9.9 days per year)²⁸. Similarly, a higher rate of absenteeism was observed for working IDDM subjects with disability than for those without disabilities (13.8 days per year versus 3 days per year).

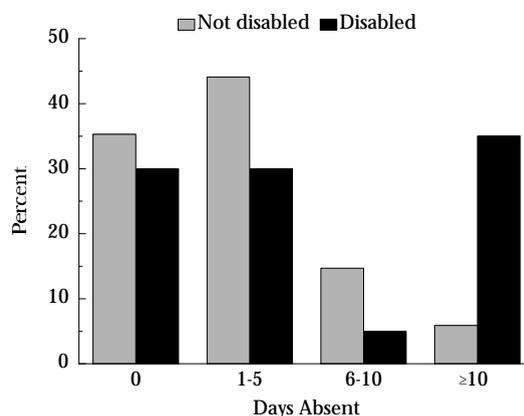
The distribution of the number of days absent from work for employed IDDM persons in the CHP IDDM Registry is shown in Figure 12.20. Excess absenteeism for disabled persons was noted for the category of ≥ 10 days absent per year but not for the categories with fewer days of absence. These data may reflect that disabled people either tend to be absent more frequently or tend to be absent for longer periods when they are away from work.

Table 12.14
Industry-Based Studies of Absenteeism in Diabetes

Ref.	Study, year	No. of diabetic employees	Absence rate of diabetic employees (days/year)	Absence rate of nondiabetic employees (days/year)
38	An insurance company, 1950	10	2.4	4.9
39	Third Ave. Transit System, 1951	40	31.6	19.6
40	Oil refinery, 1956	90	9.8	8.8
41	Dupont Co., 1956	408	10.8	5.6
42	Dupont Co., 1963	622	13.0	6.9
43	Ford Motor Co., 1959-64	273	10.5	3.5
44	Hanford Operations Co., 1974	108	6.3	7.5

Source: References are listed within the table

Figure 12.20
Frequency Distribution of Absenteeism per Year for Currently Employed IDDM Subjects, by Disability Status, 1950-64 Cohort, CHP IDDM Registry



CHP, Children's Hospital of Pittsburgh.

Source: Pittsburgh Epidemiology of Diabetes Complications Study

Table 12.15
Health Care Use by Disability Status, Age ≥18 Years, U.S., 1989

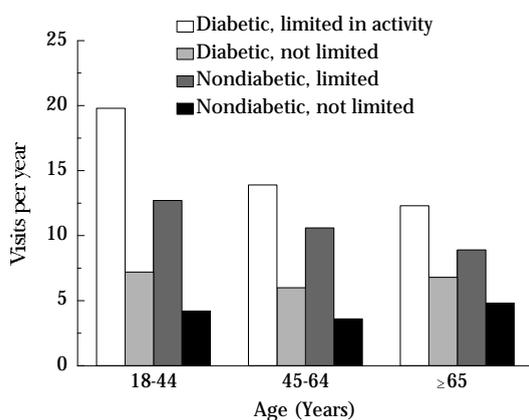
	Diabetic population		Nondiabetic population	
	Limited	Not limited	Limited	Not limited
Physician visits				
Physician contact in the past year (%)	95.7	93.2	89.0	72.0
Hospitalizations				
Hospitalized in the past year (%)	32.4	13.2	22.0	7.3
Average length of stay per discharge (days)	14.2	8.7	11.3	5.3

Source: 1989 National Health Interview Survey

DISCRIMINATION

With a higher degree of unemployment and absenteeism, there is concern that persons with diabetes may face discrimination in the workplace. Indeed, some reports suggest that this has taken place in the past^{31,45}. The extent to which disabled persons with diabetes are discriminated against is not known. The 1990 Americans with Disabilities Act, however, may increase employment possibilities for disabled persons with diabetes. This legislation seeks to expand the opportunities of disabled persons by providing standards in employee hiring and by allowing for work rule and work environment changes to meet the needs of those with disabilities.

Figure 12.21
Average Number of Physician Visits for Respondents with at Least One Visit, by Diabetes Status, Disability Status, and Age, U.S., 1989



Source: 1989 National Health Interview Survey

Table 12.16
Health Care Use Rates for IDDM Persons, by Disability Status

Type of health service	Limited	Not limited
Average number of hospital admissions per year	0.95	0.42
Average number of outpatient physician visits per year	10.34	4.63
Average number of emergency department visits per year	1.14	0.63

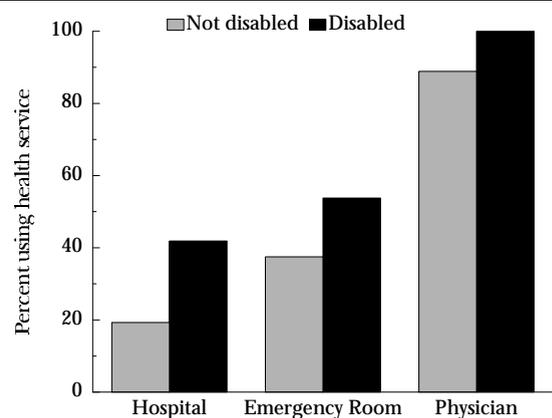
Source: Pittsburgh Epidemiology of Diabetes Complications Study

HEALTH CARE USE

Disability has concomitant effects on the use of medical services. In diabetes, a number of medical problems give rise to disability. Hence, there is a strong association between disability and the use of medical care. Disabled subjects with diabetes, in general, use health care services more frequently than nondisabled persons with diabetes. Disabled subjects with diabetes also appear to use medical care more often than disabled persons who do not have diabetes. Table 12.15 and Figure 12.21 describe this pattern for hospital and outpatient physician care.

Figure 12.22 and Table 12.16 outline the medical care/disability association for IDDM subjects in the EDC study. Persons limited in the kind or amount of work they could perform were more likely to use hospital, emergency department, and outpatient physician services. Their total number of health care con-

Figure 12.22
Percent of IDDM Subjects Using Health Care, by Type of Health Care Service and Disability Status, Pittsburgh EDC Study, 1990-92



EDC, Epidemiology of Diabetes Complications.

Source: Pittsburgh Epidemiology of Diabetes Complications Study

tacts averaged twice the figure reported by those not limited.

ACCESS TO HEALTH CARE

Shortcomings in the present health care system, such as insurance exclusions brought about through preexisting illness clauses, raise some concern about the ability of disabled persons to obtain health care when they need it. Overall, there is very little information available specific to this issue. Data on IDDM persons in the EDC study indicate that persons with activity limitations are more likely to report difficulties in obtaining medical care than those not disabled (19.6% versus 8.6%, $p=0.003$). While most subjects reporting disability had health insurance coverage (90.3%), they were more likely to be covered by individual plans than by group plans (25% versus 11.6%, $p=0.003$). As a result, they more often reported paying higher rates for insurance coverage than did those not disabled (8.7% versus 2.8%). These data suggest that economic factors could influence some of the health care decisions of disabled persons.

ECONOMIC DIFFICULTIES

Income differences have been widely noted between disabled and nondisabled persons^{4,5}. While disability rates are higher for individuals in lower socioeconomic categories, it is often difficult to distinguish

cause and effect in this relationship. The loss of income arising from severe work-limiting disabilities is a pervasive economic burden faced by disabled people. Figure 12.23 describes the change in income levels observed in the EDC study for IDDM subjects who did and did not develop disability in the 4 years since their baseline examination. Persons who were free of disability at baseline and reported a disability at 4-year followup were more likely to report a decrease in household income levels over time than were participants who remained free of disabilities (23.5% versus 14.6%). Equally important, those developing disability were also less likely to experience an increase in income level (29.4% versus 49.6%).

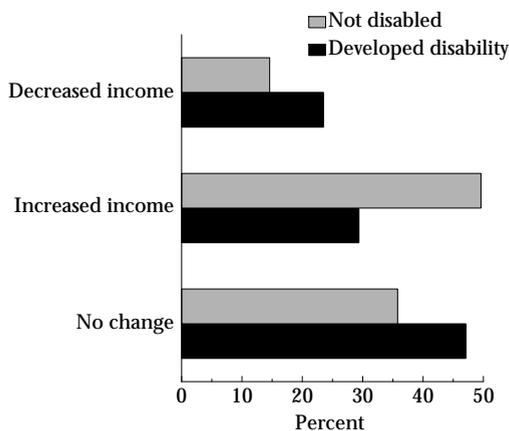
RESTRICTIONS IN NORMAL ACTIVITIES

Limitations in the normal activities of living, such as the abilities to care for oneself, to get around, and to maintain a household, have been viewed in the literature from two different perspectives. Most often, these types of limitations in ADLs or IADLs have been observed as evidence of disability. Other reports, though, have examined these types of limitations as resultant outcomes of disability. As demonstrated earlier, extended impairments in basic life activities signal a greater degree of dependency for the affected individual and an increased likelihood for institutionalization.

The 1989 NHIS examined the frequency in which certain respondents (those age 18-59 years with activity limitations and all persons age 60-69 years) required assistance in personal care (ADLs) or other routine care needs (IADLs). Overall, persons with diabetes (either NIDDM or IDDM) were more likely to report dependency in these activities than those without diabetes, even after adjusting for age (Figure 12.24). Individuals with IDDM appeared to have a markedly higher frequency of dependency in personal care needs. This degree of dependency in ADLs occurred in the young as well as in the middle-aged (Table 12.17).

Among IDDM subjects surveyed in the EDC study, about one-third of those reporting disabilities (limitations in the kind or amount of work they could perform) had difficulty in performing at least one ADL (Table 12.18). Fifty-seven percent reported at least one restriction in the IADLs. Seventy-five percent reported some type of functional capacity limitation. The impairments most frequently cited by the respondents were difficulty in lifting heavy items; difficulty in doing heavy housework such as scrubbing floors and windows; difficulty in standing for long periods

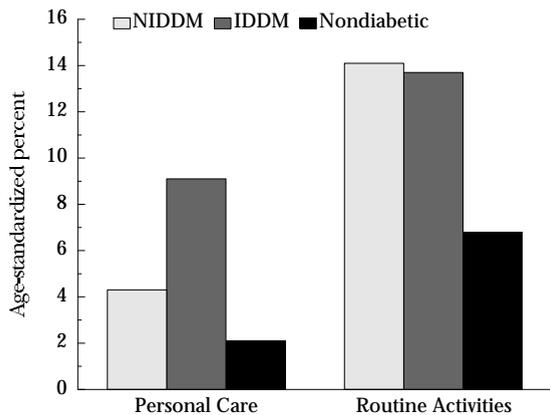
Figure 12.23
Percent of IDDM Subjects with a Change in Income Level in 4 Years, by Disability Status, Pittsburgh EDC Study



EDC, Epidemiology of Diabetes Complications. Change in income level is calculated from the baseline examination to the 4-year follow-up examination.

Source: Pittsburgh Epidemiology of Diabetes Complications Study

Figure 12.24
Age-Standardized Percent of Persons Reporting Difficulties in ADLs and IADLs, by Diabetes Status, U.S., 1989



ADL, activities of daily living; IADL, instrumental activities of daily living.
 Source: 1989 National Health Interview Survey

of time; and difficulty in stooping, crouching, or kneeling.

QUALITY OF LIFE

Disabled persons face a number of practical obstacles in everyday life⁴. Physical, social, emotional, and other barriers exist and affect disabled people to varying degrees. Some, such as occupational problems, are easy to identify from a research perspective. Others, including the day-to-day burdens that disabled people encounter, are more difficult to quantify. It is likely that many persons with disabilities live with uncertainty about what lies ahead. While there are few

Table 12.17
Percent of Persons Reporting Restrictions in Normal Activities, by Type of Activity and Age, U.S., 1989

Activity and age (years)	NIDDM	IDDM	Nondiabetic population
Personal care needs (e.g., bathing, eating, dressing)			
18-44	3.9	8.4	1.8
45-69	5.0	10.3	2.5
Other routine needs (e.g., household chores, shopping, etc)			
18-44	14.1	12.5	7.1
45-69	14.1	15.7	6.3

Source: 1989 National Health Interview Survey

adequate measures to assess the importance this plays in the lives of disabled persons and the manner in which they cope with it, one common practice in the health care literature is to address the quality of life of the affected individuals. Quality-of-life measures often survey a much larger range of experiences than found in a typical disability evaluation.

Assessments of health-related quality of life, for example, examine the impact of disease, disability, and health care treatments over a spectrum of five broad concepts: opportunity, health perceptions, functional states, impairments, and duration of life⁴⁶. These concepts touch on diverse disciplines, ranging from physical functioning to social functioning to mental health to disadvantage to disease symptomatology. A variety of health-related quality-of-life instruments exist⁴⁶. While many surveys try to focus on all aspects of health-related quality of life by using a health index or health profile, a number of studies consider only one area, such as physical functioning or health perception. Both types of measures have been applied to evaluate quality of life in persons with diabetes.

Table 12.18
Percent of Disabled IDDM Subjects Reporting Restrictions in Normal Activities by Type of Activity, Pittsburgh EDC Study, 1990-92

Type of activity	Percent
Activities of daily living	33.3
Bathing and showering	7.5
Dressing	11.8
Eating	10.8
Getting in/out of chairs/bed	14.0
Getting outside	12.9
Using the toilet	4.3
Instrumental activities of daily living	57.0
Preparing meals	17.2
Shopping for personal items	18.7
Managing money	14.4
Using the telephone	6.5
Doing heavy housework	49.5
Doing light housework	12.0
Functional capacity limitations	75.3
Walking for one-quarter mile	36.6
Walking up to 10 steps	23.7
Standing for 2 hours	43.0
Sitting for 2 hours	22.8
Stooping, crouching, kneeling	42.4
Reaching over your head	25.0
Reaching out to shake a hand	7.6
Grasping or handling objects	30.8
Lifting or carrying 25 lbs.	50.0
Lifting or carrying 10 lbs.	25.8

EDC, Epidemiology of Diabetes Complications.

Source: Pittsburgh Epidemiology of Diabetes Complications Study

HEALTH PERCEPTIONS

A common indicator of health perception is the self-rating of health. Subjects typically are asked to rate their current health status as excellent, very good, good, fair, or poor. Relatively few persons with NIDDM or IDDM in the 1989 NHIS rated their health as excellent (5.8% and 12.2%, respectively) (Appendix 12.4). A large proportion of respondents with NIDDM, in fact, rated their health as either fair (30.2%) or poor (19.9%). These patterns contrasted sharply with the responses of the nondiabetic population even after adjusting for age (Figure 12.25). A similar experience was reported for older adults in Beaver Dam, WI⁴⁷. Both insulin-using and noninsulin-using diabetic persons had lower health scores than the general population without diabetes.

Higher frequencies of morbidity and disability in the diabetic population are likely to account for some proportion of the lower health ratings of diabetic subjects. A survey of 170 adults with IDDM, for example, illustrated that patients with nephropathy had lower health perceptions and increased worry over their health than patients with no diabetic complications⁴⁸. Moreover, diabetic individuals with disability report markedly lower levels of health than persons without disabilities. Table 12.19 shows the distribution of diabetic subjects in the 1989 NHIS by self-reported health status and the presence of disability. Figure 12.26 shows the distribution of IDDM subjects in the EDC study by their health ratings and disability status. About half of the IDDM individuals with dis-

Table 12.19

Percent of Adults by Self-Reported Health Status and Disability Status, Age ≥18 Years, U.S., 1989

Health status	Diabetes population		General population	
	Limited	Not limited	Limited	Not limited
Excellent	2.0	11.4	9.4	40.0
Very good	6.3	24.3	17.8	31.9
Good	24.8	38.8	31.5	23.0
Fair	35.2	22.0	26.5	4.7
Poor	31.7	3.6	14.9	0.5

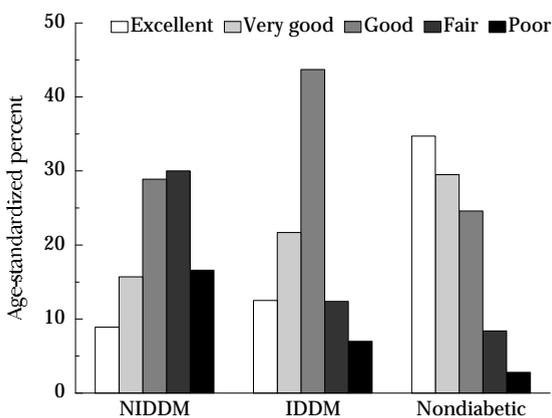
Source: 1989 National Health Interview Survey

ability rated their health as either fair or poor. In contrast, only 11% of the respondents without disabilities indicated the same.

HEALTH PROFILES

A more comprehensive assessment of quality of life may be obtained from health profiles. The health profiles most frequently used include the Sickness Impact Profile (SIP) and the Short Form Health Survey (SF-36). Both examine an extensive number of quality-of-life domains, involving physical and psychosocial functioning, impairment and health perceptions⁴⁶. The Diabetes Quality of Life (DQOL) measure, developed in the Diabetes Control and Complications Trial (DCCT), is another instrument more specific to the issues facing persons with diabetes. It includes four scales: satisfaction, impact, diabetes-related worries, and social/vocational worries.

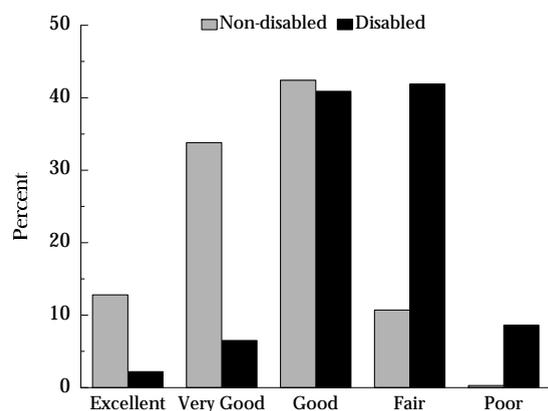
Figure 12.25
Self-Reported Health Status for Diabetic and Nondiabetic Persons, U.S., 1989



Data are age-standardized using three age groups and the overall NHIS cohort as a standard population.

Source: 1989 National Health Interview Survey

Figure 12.26
Self-Reported Health Status by Disability Status for IDDM Subjects, Pittsburgh EDC Study, 1990-92



EDC, Epidemiology of Diabetes Complications.

Source: Pittsburgh Epidemiology of Diabetes Complications Study

Overall, it appears that persons with diabetes have poorer health status and quality of life, as measured by health profiles, than do persons without diabetes. Among the 9,385 adults participating in the Medical Outcomes Study, the 844 subjects with diabetes scored markedly lower on four of the six health measures in the SF-20 (health perceptions, physical, role, and social functioning) compared with patients with no chronic conditions (Figure 12.27)⁴⁹. There was no difference in the mental health and bodily pain domains. The majority of the diabetic subjects in the Medical Outcomes Study had NIDDM. Similarly, 393 persons with NIDDM in the San Antonio Heart Study population reported higher rates of functional impairment than did 486 nondiabetic controls (36.6% versus 16.7%)⁵⁰. Functional impairment was defined in this report as a SIP score of 2.0% or higher.

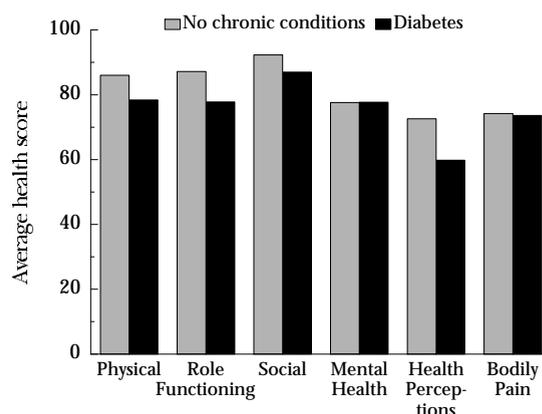
The assessment of quality of life among disabled persons with diabetes, as determined from health profiles, has not yet been examined. Indications from two studies, however, suggest that individuals with diabetic complications have diminished levels of quality of life. In the San Antonio, TX study, diabetic persons with vascular complications had a higher prevalence of functional impairment (45.9%) than individuals without complications (31.8%)⁵⁰. In a study of 240 persons with IDDM and NIDDM attending an outpatient clinic, the SF-36 and the DQOL measures were administered. In both measures, the quality of life of subjects with severe diabetes complications was lower than that for subjects with no complications⁵¹.

HEALTH PREFERENCES

Another type of assessment of health-related quality of life incorporates the explicit values or preferences of surveyed individuals for various types of health. By considering the relative desirability that individuals place on health, these types of assessments allow one to combine the different domains of health-related quality of life into a single index⁴⁶. The measurement of health state preferences also permits the integration of quality of life with quantity of life in health care evaluations⁴⁶.

The health states of diabetic subjects in the 1982-84 followup of the First National Health and Nutrition Examination Survey were examined⁵² and their responses to the health states considered in the Health

Figure 12.27
Average Health Scores in the SF-20 for Diabetic Patients and Patients with No Chronic Conditions by Type of Health Measure, 1989



Source: Medical Outcomes Study; Reference 49

Utility Index (HUI)⁵³ were mapped. In general, diabetic subjects had lower levels of health-related quality of life (as estimated by the preference-based measures of the HUI) than did persons without diabetes. The age-adjusted HUI score for diabetic subjects treated and not treated with insulin was 0.61 and 0.70, respectively, compared with a score of 0.79 for nondiabetic persons. The HUI scales health from a score of 0 (assigned to death) to a score of 1 (assigned to complete health). The association between diabetes complications and HUI scores was mixed. Diabetic subjects with cataracts, stroke, or hypertension had markedly lower HUI scores (poorer quality of life) than did persons without these complications. No significant differences were noted, however, among persons with glaucoma, or chronic heart disease.

A similar overall finding using a different survey was reported from the Beaver Dam, WI Health Outcomes Study⁴⁷. Age-adjusted time-trade-off scores were comparatively lower for diabetic subjects treated and not treated with insulin than for persons without diabetes.

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APPENDICES

Appendix 12.1
Percent of Persons Reporting an Activity Limitation by Sex, Age, and Diabetes Status, U.S., 1989

Sex and age	NIDDM	IDDM	Nondiabetic
All adults	56.3	42.9	15.6
Males	53.8	49.8	14.9
Females	58.0	35.1	16.1
Age (years)			
18-44	45.0	43.4	8.5
45-64	55.0	39.8	21.3
≥65	60.0		33.5

Source: 1989 National Health Interview Survey

Appendix 12.2
Percent of Adults Reporting Activity Limitations, by Type of Activity, Sex, Age, and Diabetes Status, U.S., 1989

	NIDDM	IDDM	Nondiabetic
Unable to carry on major activity	20.6	13.9	4.4
Males	24.3	11.2	5.2
Females	17.9	16.9	3.6
Age (years)			
18-44	17.2	12.8	2.1
45-64	25.7	20.0	7.6
≥65	16.8		7.8
Limited in kind or amount of major activity	19.3	20.1	5.9
Males	15.9	28.9	5.1
Females	21.8	10.2	6.7
Age (years)			
18-44	19.3	21.8	3.6
45-64	16.8	10.7	7.9
≥65	21.6		11.8
Limited, but not in major activity	16.4	8.9	5.2
Males	13.7	9.7	4.6
Females	18.2	8.0	5.8
Age (years)			
18-44	8.5	8.9	2.7
45-64	12.5	9.1	5.8
≥65	21.6		14.1

Source: 1989 National Health Interview Survey

Appendix 12.3
Percent of Adults Reporting Restricted Activity Days in the Past 2 Weeks by Type of Restriction, Sex, Age, and Diabetes Status, U.S., 1989

Sex and age	NIDDM	IDDM	Nondiabetic
Any type of restriction	21.7	20.0	10.2
Males	18.2	19.9	8.9
Females	24.3	20.1	11.4
Age (years)			
18-44	23.1	18.7	9.8
45-64	20.9	27.0	10.2
≥65	22.1		12.1
Bed days	12.3	12.9	5.7
Males	9.9	15.1	4.6
Females	14.1	10.1	6.6
Age (years)			
18-44	16.0	11.1	5.8
45-64	11.4	22.3	5.7
≥65	12.3		5.4
Work loss days*	10.8	12.3	6.5
Males	8.9	12.6	5.8
Females	13.0	11.6	7.3
Age (years)			
18-44	11.8	12.7	6.9
45-64	10.5	8.8	5.5
≥65	10.2		4.3
Other restricted activity days	12.2	11.0	5.2
Males	9.7	9.4	4.1
Females	14.0	12.9	6.1
Age (years)			
18-44	11.1	11.3	4.4
45-64	10.8	9.5	5.5
≥65	13.7		7.7

* Data on work-loss days pertain to currently employed persons only.

Source: 1989 National Health Interview Survey

Appendix 12.4

Percent Distribution of Adults, by Self-Reported Health Status, Sex, Age, and Diabetes Status, U.S., 1989

Sex and age	NIDDM	IDDM	Nondiabetic
All adults			
Excellent	5.8	12.2	35.2
Very good	13.6	25.9	29.7
Good	30.5	40.8	24.3
Fair	30.2	14.3	8.1
Poor	19.9	6.9	2.7
Males			
Excellent	7.8	14.6	38.9
Very good	15.5	31.2	29.7
Good	29.5	37.2	21.7
Fair	27.8	10.9	6.8
Poor	19.4	6.1	2.8
Females			
Excellent	4.4	9.4	31.8
Very good	12.3	19.8	29.6
Good	31.3	44.8	26.6
Fair	31.8	18.1	9.3
Poor	20.2	7.9	2.6
Age 18-44 years			
Excellent	11.7	11.8	42.2
Very good	17.6	29.6	32.1
Good	27.1	38.2	20.1
Fair	30.1	16.0	4.7
Poor	13.4	4.4	1.0
Age 45-64 years			
Excellent	5.2	13.9	29.6
Very good	13.0	4.7	27.9
Good	31.9	55.6	28.0
Fair	29.0	4.8	10.6
Poor	20.9	21.1	4.0
Age ≥65 years			
Excellent	5.0		17.5
Very good	13.2		23.1
Good	30.1		34.5
Fair	31.2		17.5
Poor	20.5		7.4

Source: 1989 National Health Interview Survey