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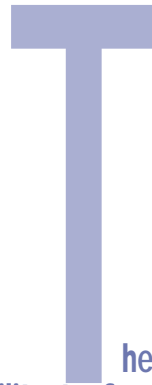
■

Chapter ten

Rehabilitation & quality of life

The house of my body has spoken
often as you rebuild me like blocks,
and promise to come visit
when I'm finally adjusted on safe land,
and am livable, joist to joist
with storm windows and screens...

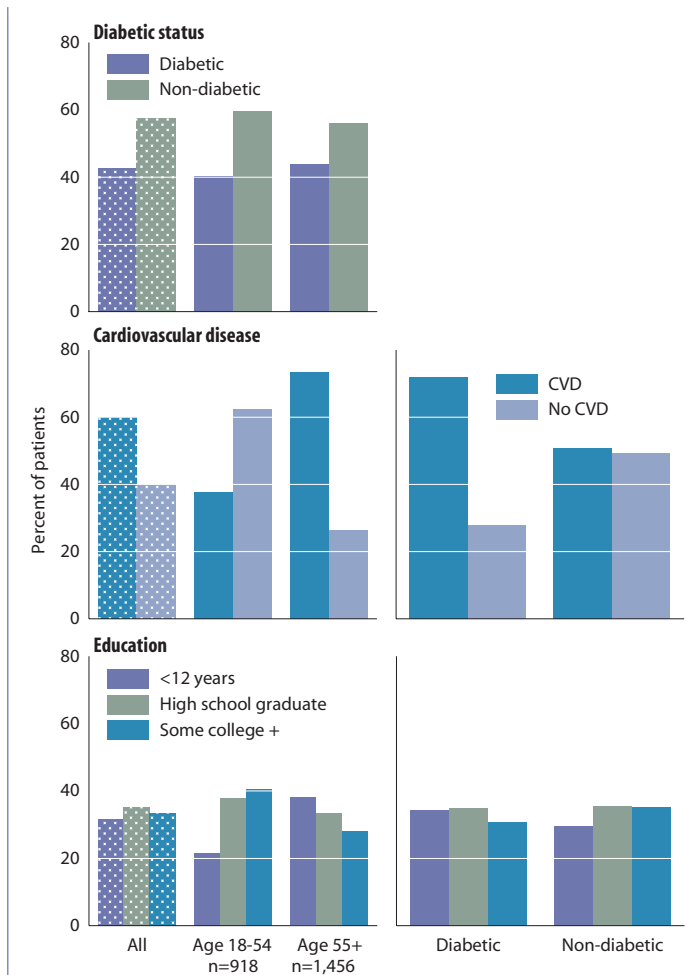
Anne Sexton, "There You Were"



The goal of rehabilitation is to help individuals maximize their ability to function in their usual living environment.

Perceived health status reflects individuals' own view of how they are doing, and how they feel about their health and its effects on their life. Both rehabilitation and quality of life (QOL) are closely related to the ability to take part in gainful employment activities. ■ The mission of the USRDS Rehabilitation/QOL Special Studies Center is to increase understanding of the influences on rehabilitation and quality of life outcomes among patients with chronic kidney disease. In addition to the importance of these outcomes in patients' own lives, maximizing individuals' ability to function independently and to engage in productive activities such as employment is cost-effective for the larger society. ■ Rehabilitation and quality of life outcomes are less easily "counted" than patient events such as transplantation, hospitalization, and death. In this chapter we rely on two sources of data. The first is patient-reported health status and employment information from the Wave 2 USRDS Dialysis Morbidity and Mortality Study (DMMS), conducted in 1996 in a 25 percent random sample of U.S. dialysis providers, which we use in Figures 10.1–21. All patients in these facilities who started peritoneal dialysis treatment, and a 20 percent sample of patients who started hemodialysis treatment, were asked to complete a patient questionnaire close to the beginning of their therapy; questions included perceived health status, perceived ability to work, employment status, and desire to work. ■ We also look here at Medicare payment data from 1998–2000 on physical therapy services and cardiac rehabilitation services received by U.S. ESRD patients. These data were linked with patient characteristics from the Patient, Patient History, and Medical Evidence files (see Appendix B for information on these files). We describe characteristics of patients who received therapeutic exercise, neuromuscular education, and gait training (three types of physical therapy services), as well as monitored and non-monitored exercise (two types of cardiac rehabilitation services). Variations by patient age and diabetic status are shown for all health status and employment outcomes as well as for rehabilitation services. ■ Figure 10.1 presents sociodemographic and clinical characteristics that may contribute to variations in the health status that patients report or to their work and disability status. Among patients answering the Wave 2 questionnaire, 62 percent are age 55 (a frequent cut-point for early retirement eligi-

CHAPTER HIGHLIGHTS ■ Figures 10.2–17 Diabetes is more important than age as a source of variation in dialysis patients' self-reported health status. ■ Figures 10.18–21 As dialysis patients' educational status increases, it is more likely at the start of ESRD therapy that patients who describe themselves as "able to work," are employed, and would like to return to work even though they describe themselves as currently "not able to work." ■ Figures 10.22–29 Two-thirds or more of the patients who receive physical therapy and cardiac rehabilitation services are age 55 or older, and 40–50 percent are diabetic.



10.1 Patient distribution, by demographic characteristics

DMMS Wave 2 data (1996).

bility) or above, and for 43 percent diabetes is the primary cause of renal failure. The proportion of patients with diabetic ESRD is not significantly different between older and younger patients. ■ Since patients beginning ESRD therapy tend to be older and diabetic, factors which both increase the risk of cardiovascular disease, it is not surprising that 60 percent of the surveyed patients have cardiovascular comorbidity at the start of treatment. ■ Educational status serves as a proxy measure of socioeconomic status. As in the general population, educational status is likely to be associated with the outlook of ESRD patients on their health status, and is likely as well to shape employment opportunities. Overall, Wave 2 patients are equally distributed among the education categories. Younger patients tend to report more education than older patients, which may reflect a generational change. The majority of patients in the study with diabetic ESRD have a high school diploma or less, while the majority of those without diabetes have received a diploma or attended college. ■ In the remainder of the chapter, then, we show that variations in health status associated with age and diabetes are also likely to reflect the influence of cardiovascular comorbidity, while variations associated with age may also reflect some influence of lower educational (socioeconomic) status.

Self-reported health status

Multiple studies have shown that dialysis patients' reported health status is associated with clinical outcomes, including hospitalization and survival. Because it may identify areas to target for early intervention, health status information at the start of dialysis treatment is particularly important. DMMS Wave 2 measured health status using the Kidney Disease Quality of Life (KDQOL) instrument, which includes questions measuring both "generic" (Figures 10.2–9) and "disease-specific" health status (Figures 10.10–17).

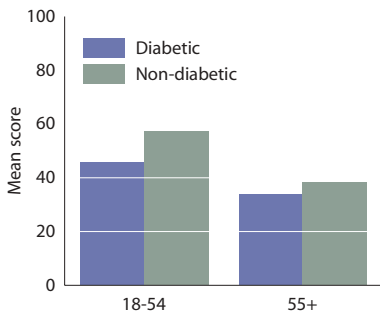
Generic health status domains encompass a spectrum of physical and mental health concepts that apply broadly across impairments, illnesses, and patient populations. Disease-specific domains reflect special states and concerns of patients with a particular diagnosis, especially symptoms of that disease and treatment effects.

On this spread we present responses by age and diabetic status. Data on generic health status, which summarize important aspects of functioning in daily life, show younger patients reporting better health status compared to older patients (Figures 10.2–9). This age difference is not marked, however, with the exception of patient-reported physical functioning.

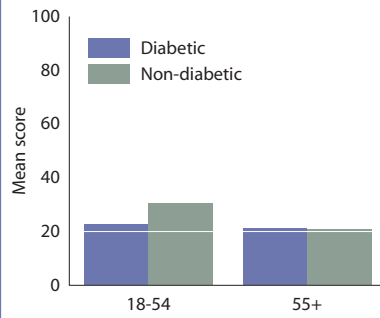
An effect of diabetic status on patient-reported health status is evident among younger patients for physical functioning, role-functioning physical, general health perceptions, social functioning, and energy/fatigue.

The relative heights of the bars in these figures indicate that patient-reported health status is lowest in the domain of role-functioning physical, which reflects patients' views of the extent to which their physical health interfered with work or other activities during the past four weeks. Other generic health status domains with lower self-reported health status are general health perceptions and energy/fatigue.

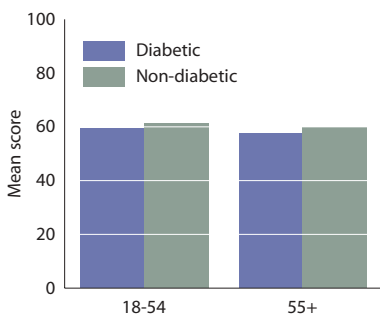
10.2 · Physical functioning score, by age & DM status



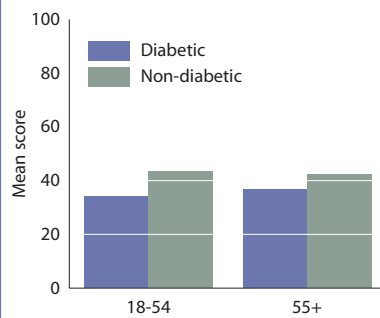
10.3 · Role-physical score, by age & DM status



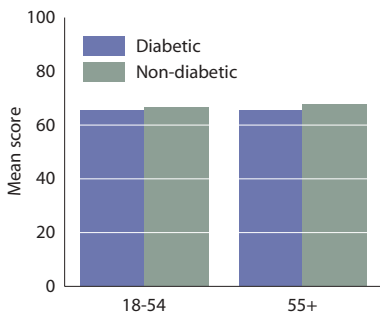
10.4 · Pain score, by age & DM status



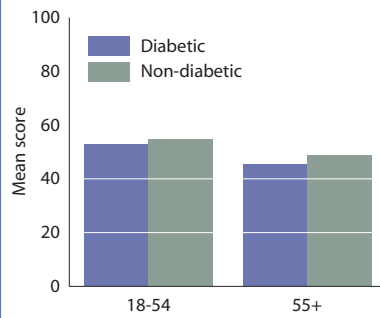
10.5 · General health score, by age & DM status



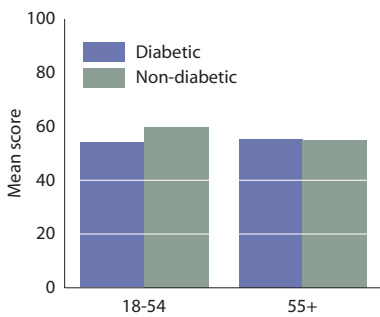
10.6 · Emotional well-being score, by age/DM status



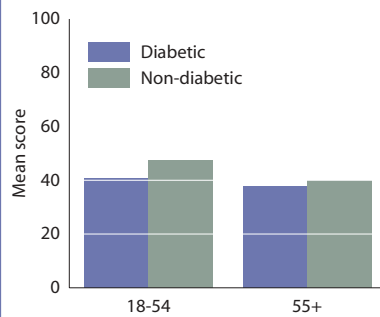
10.7 · Role-emotional score, by age & DM status



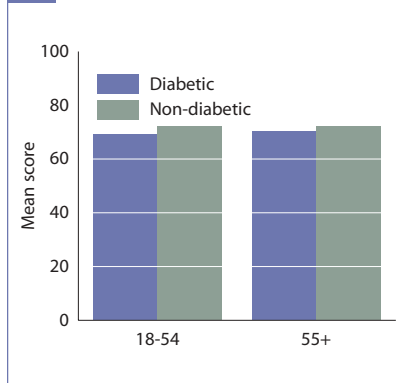
10.8 · Social function score, by age & DM status



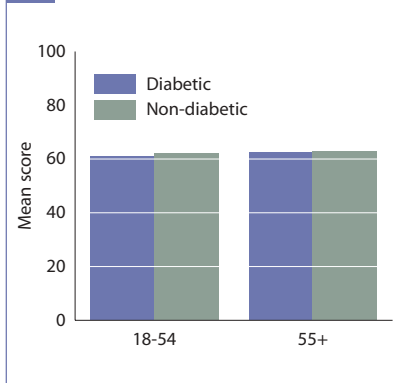
10.9 · Energy/fatigue score, by age & DM status



10.10 - Symptoms/problems score, by age/DM status

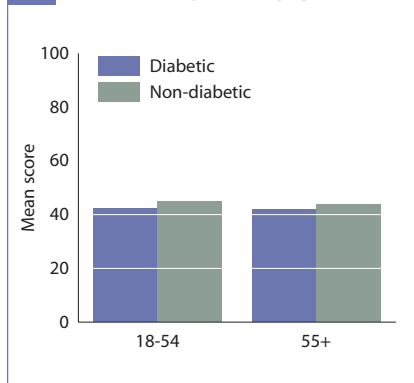


10.11 - Effects of kidney disease, by age & DM status

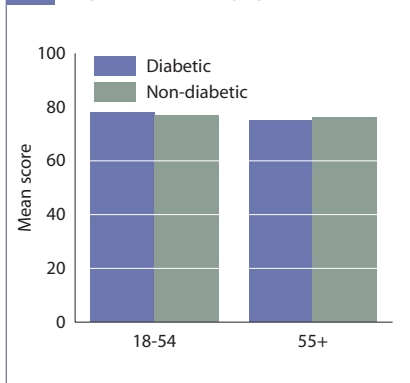


Patient responses for eight disease-specific scales from the KDQOL instrument also tend to be similar by age (Figures 10.10–17). An age and diabetes interaction effect is evident in perceived social support, with scores lower in young patients with diabetes than in those without, and similar in older patients regardless of diabetic status. In the remaining domains, however, there is little difference between the average scores of diabetic and non-diabetic patients.

10.12 - Burden of kidney disease, by age & DM status

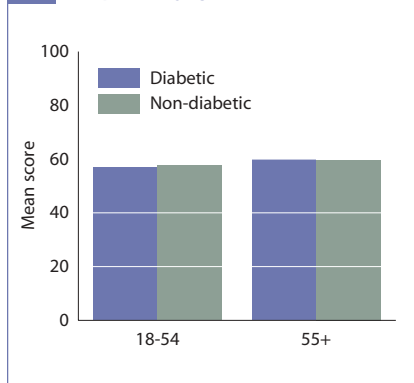


10.13 - Cognitive function, by age & DM status

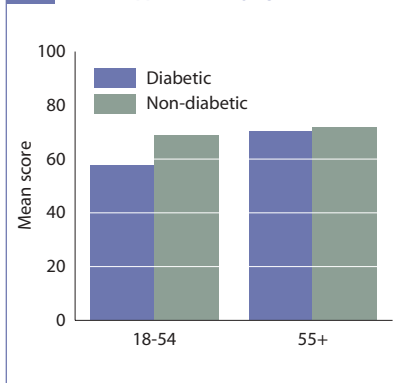


The disease-specific health status domain for which scores are lowest is burden of kidney disease, which evaluates patients' feelings that kidney disease interferes too much with their lives, takes too much time, makes them feel frustrated, and/or makes them feel that they are a burden on their families; a low score indicates low health-related quality of life as measured by this scale. Two other domains for which scores indicate relatively lower health-related quality of life are effects of kidney disease on daily life and sleep.

10.14 - Sleep score, by age & DM status



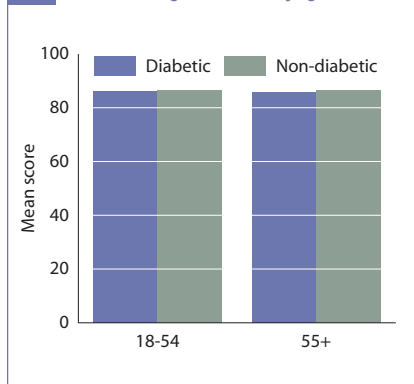
10.15 - Social support score, by age & DM status



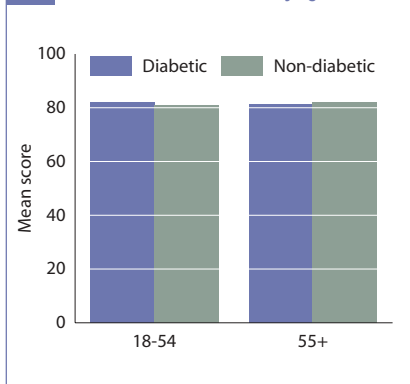
Perceived staff encouragement and patient satisfaction with care are rated relatively high by DMMS Wave 2 patients who responded to the Patient Questionnaire.

■ Figures 10.2–17 DMMS Wave 2 data (1996).

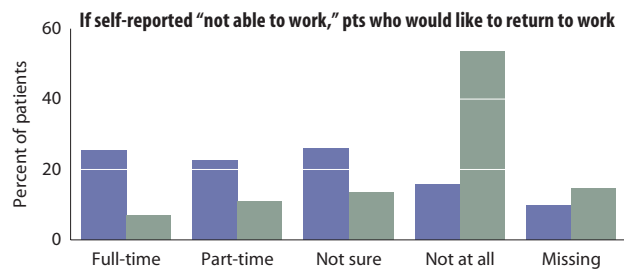
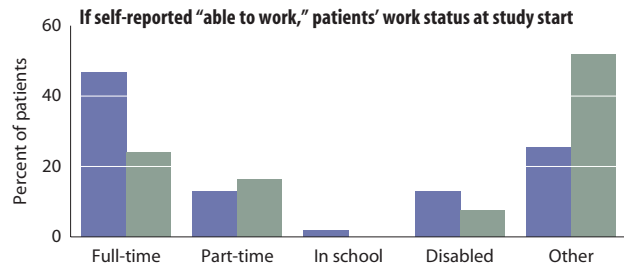
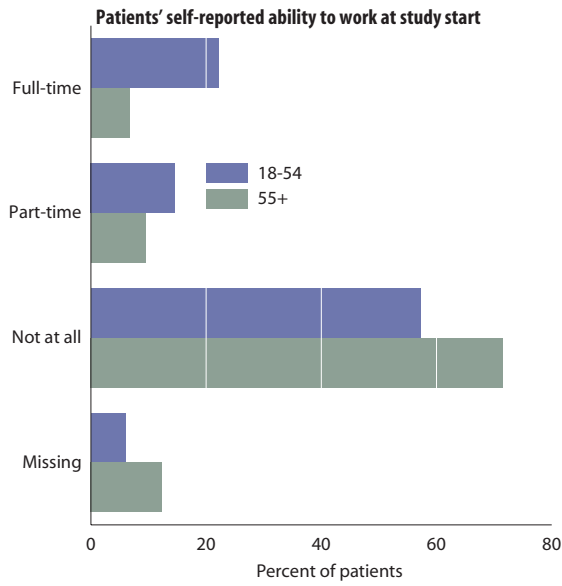
10.16 - Staff encouragement score, by age & DM status



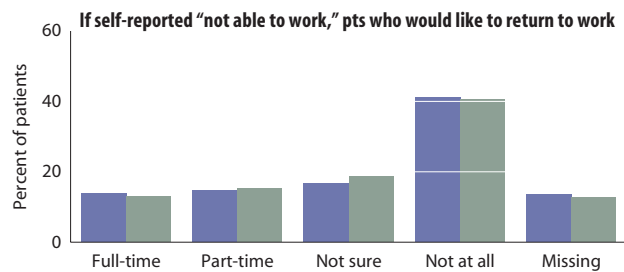
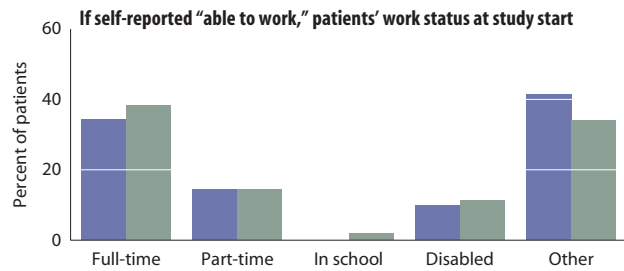
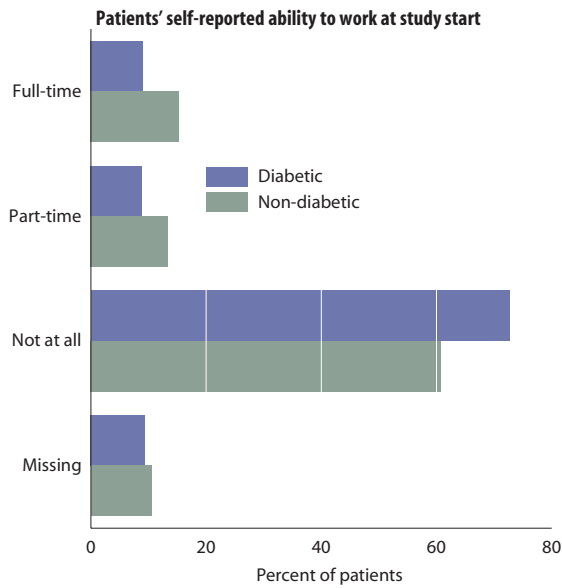
10.17 - Patient satisfaction score, by age/DM status



10.18 • Self-reported ability to work, by age



10.19 • Self-reported ability to work, by diabetic status



Work & disability

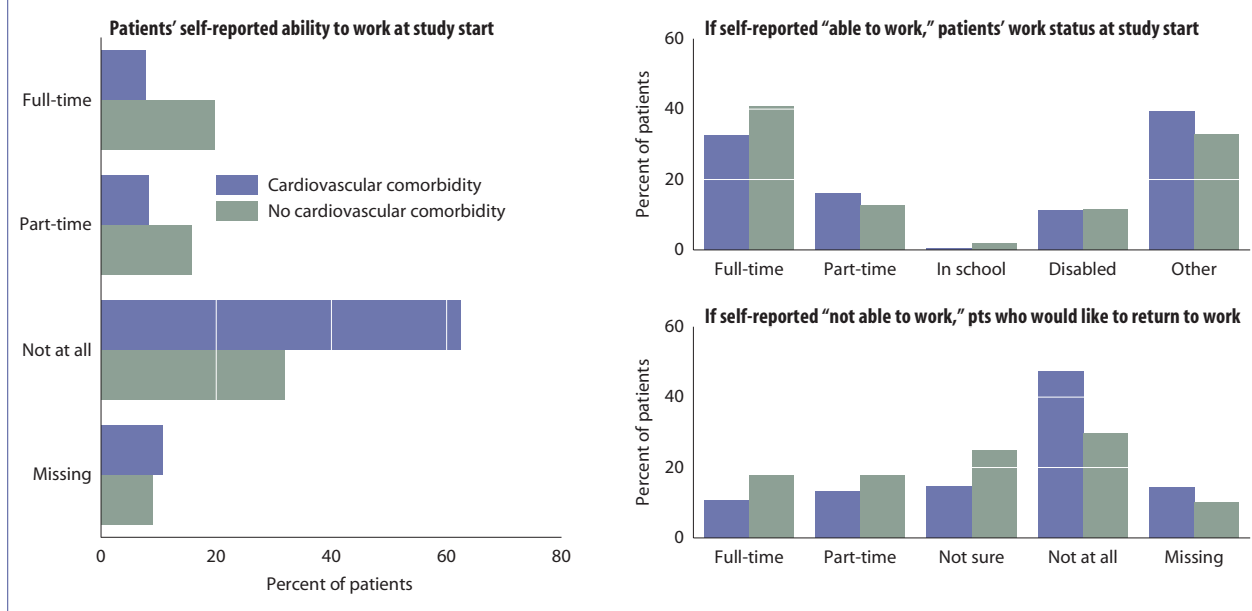
We look here at patient responses to the DMMS Wave 2 question "Are you able to work-full time, part time, or not at all?"

Even among younger patients (ages 18–54) in the study, only 37 percent say they are able to work (Figure 10.18); of these, 47 percent report working full-time and 13 percent part-time, while 13 percent say they are disabled. Older patients are slightly more likely to say they can work part-time rather than full-time; of those saying they are able to work, 24 percent work full-time and 17 percent part-time, while 7.6 percent say they are disabled.

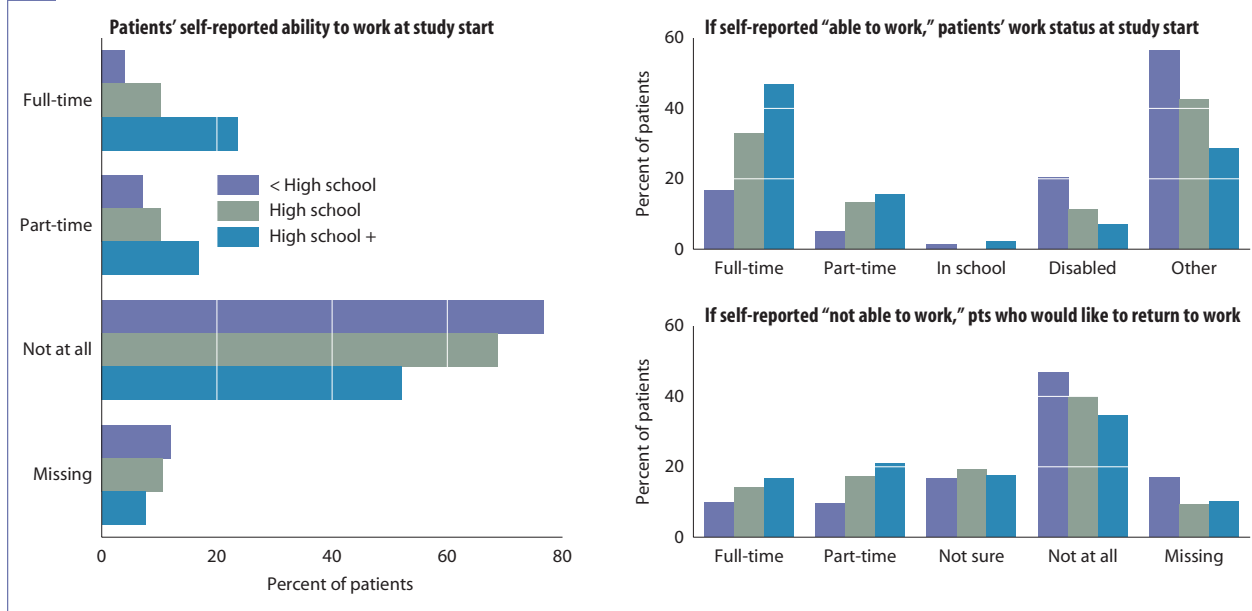
Among younger patients reporting that they cannot work, one-quarter say they would like to return to work full-time, and 23 percent part-time; 26 percent are unsure. Almost half of these patients thus express interest in returning to employment. Only 16 percent do not want to return to work, compared to more than half of the older patients who say they are unable to work.

Compared to non-diabetic patients, diabetics are less likely to report being able to work but, if they do answer affirmatively, are almost equally likely to be working (Figure 10.19). A similar pattern is evident for patients with and without cardiovascular comorbidity (Figure 10.20). Among patients reporting that they are unable to work, diabetic status has virtually no association with

10.20 • Self-reported ability to work, by cardiovascular comorbidity



10.21 • Self-reported ability to work, by education level

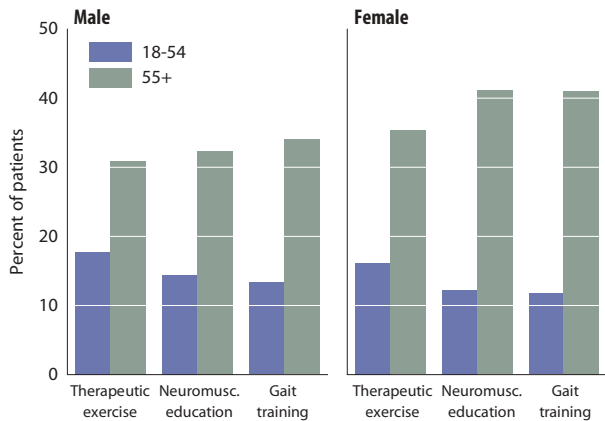


reported desire to return to work, but patients with cardiovascular comorbidity are less likely than those without it to want to return to work.

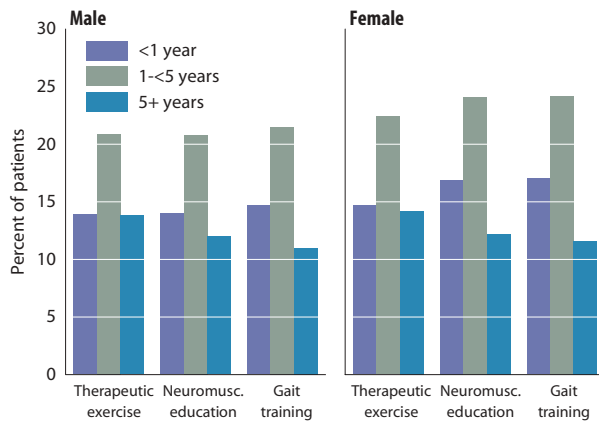
Patients with more education are more likely to report being able to work full-time or part-time (Figure 10.21). Among those who say they can work, work status at study start is directly related to educational status. Patients with fewer than 12 years of school are most likely to report that they are disabled, and patients with post-high school education are least likely. Among patients unable to work, those with more education are more likely to report a desire to return to work.

■ Figures 10.18–21 DMMS Wave 2 data (1996).

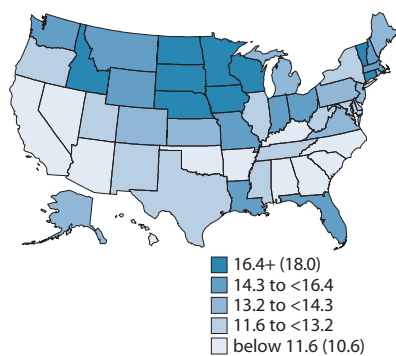
10.22 - Age & gender distribution of patients receiving physical therapy



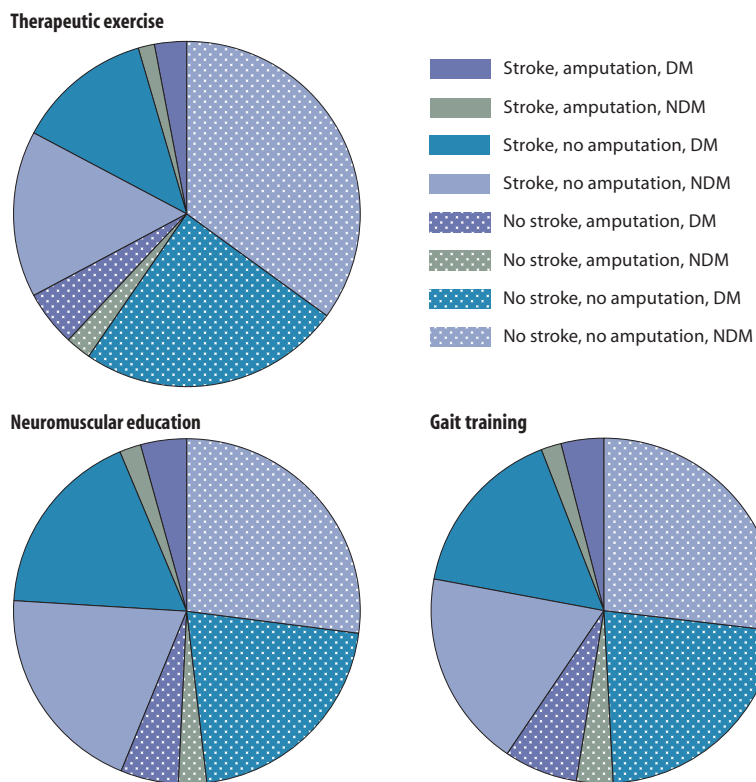
10.23 - Gender & vintage distribution of patients receiving physical therapy



10.24 - Patients receiving physical therapy (%)



10.25 - Distribution of stroke, amputation, & diabetic status for patients receiving physical therapy (%)



Rehabilitation services

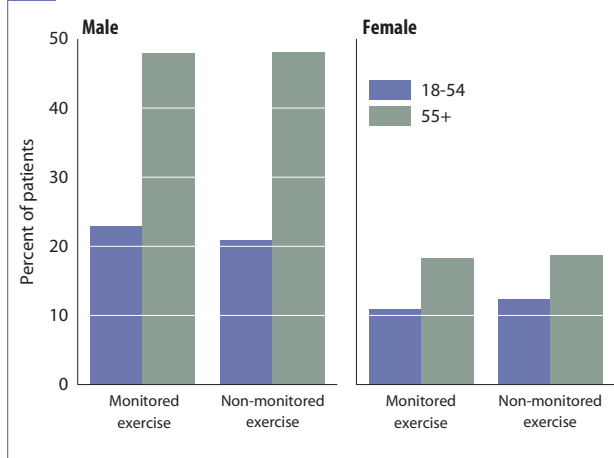
We present data here from 1998–2000 institutional and physician/supplier claims for patients receiving selected physical therapy or cardiac rehabilitation services. This information is not restricted to a particular sample of patients, as in the DMMS Wave 2 data. Most of the claims apply to dialysis patients, although a small percentage of patients had a transplant at the time of service (1.3–1.8 percent of those receiving physical therapy, and 2.6–2.8 percent of those receiving cardiac rehabilitation).

During the study interval, 57,621 patients had therapeutic exercise, 15,928 patients had neuromuscular education, and 26,447 patients had gait training. Patients age 55 and older account for 66, 73, and 75 percent of those receiving each of the three therapies, respectively (Figure 10.22). Men and women are equally represented among both older and younger patients. And recipients of all three types of physical therapy services are most likely to have a vintage on ESRD of between one and five years (Figure

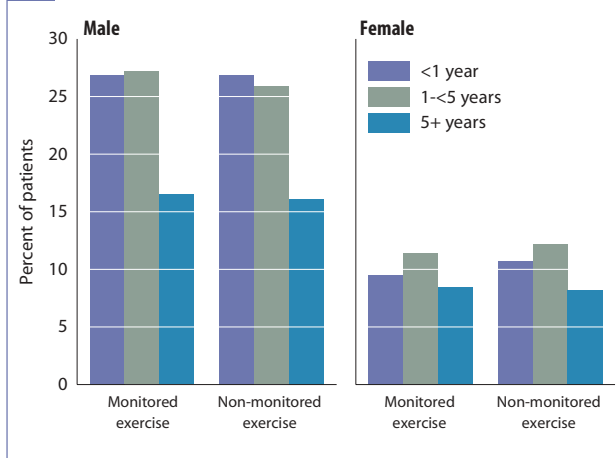
10.23). The likelihood of receiving physical therapy or cardiac rehabilitation services is greater for patients living in Vermont, the Upper Midwest, and the Rocky Mountain states (Figures 10.24 and 28).

At least 65 percent of those receiving each type of physical therapy have diabetes, have sustained a stroke, or have undergone amputation (Figure 10.25). Patients are more likely to have diabetes alone, stroke alone, or diabetes and stroke combined than to have had an amputation.

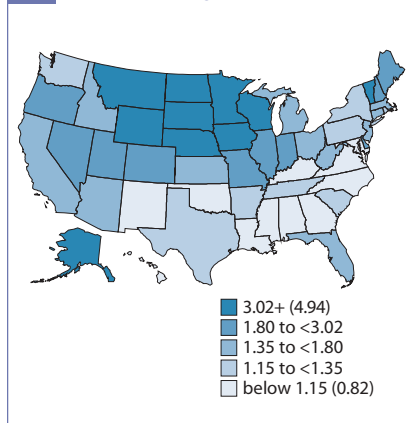
10.26 · Age & gender distribution of patients receiving cardiac rehabilitation



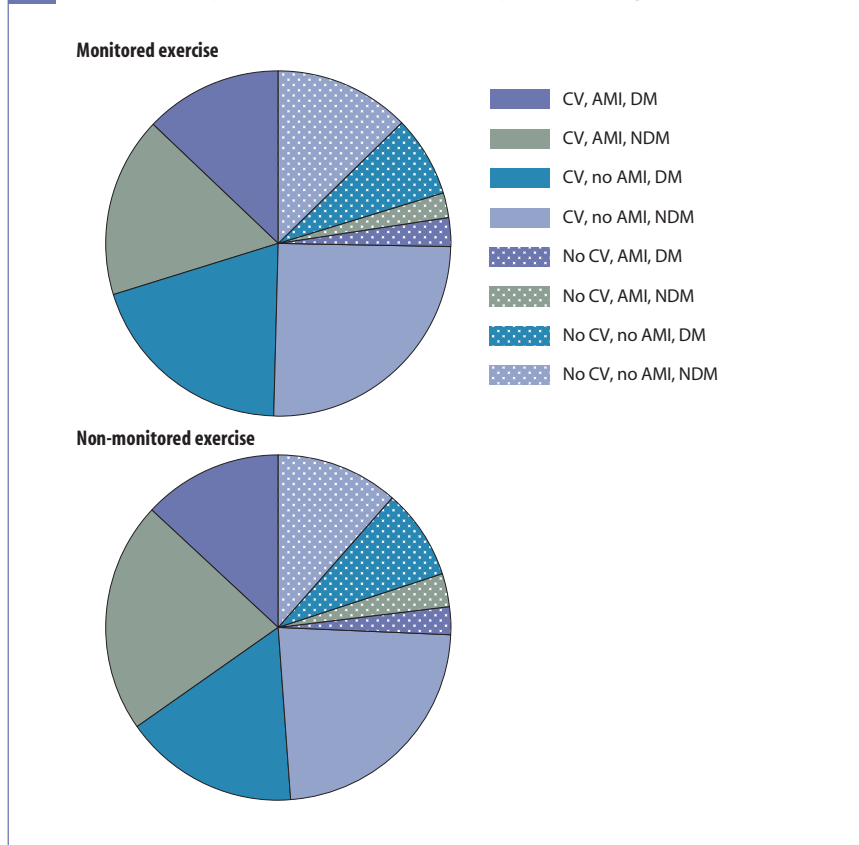
10.27 · Gender & vintage distribution of pts receiving cardiac rehabilitation



10.28 · Patients receiving cardiac rehabilitation (%)



10.29 · Distribution of CV procedure, AMI, & diabetic status for patients receiving cardiac rehabilitation (%)



During the study interval, 740 patients had monitored exercise and 3,405 patients had non-monitored exercise. Two-thirds of these patients are age 55 or older (Figure 10.26). Older men account for almost half of the patients receiving this type of service, and in general men are most likely to receive cardiac rehabilitation, regardless of age or vintage.

A large share of the services is given to patients on ESRD therapy for less than five years (Figure 10.27). Three-fourths of the patients receiving cardiac rehabilitation services have undergone a cardiovascular procedure; 62 percent are diabetic and/or have sustained an AMI (Figure 10.29).

■ All figures period prevalent ESRD patients, April 1, 1998 to December 31, 2000. ■ Figures 10.22-23 patients age 18 & older. ■ Figure 10.24 patients receiving physical therapy services, 1998-2000 combined, by state; unadjusted. ■ Figure 10.25 patients receiving physical therapy services, 1998-2000 combined; adjusted for age, gender, & race. ■ Figures 10.26, 27, & 29 patients receiving cardiac rehabilitation services, 1998-2000 combined. ■ Figure 10.28 patients receiving cardiac rehabilitation services, 1998-2000 combined, by state; unadjusted.

chapter summary

INTRODUCTION ■ **Figure 10.1** Because education (a measure of socioeconomic status) influences rehabilitation and quality of life outcomes, and there is little national information about the educational status of dialysis patients, it is of interest that among DMMS Wave 2 patients almost equal percentages had completed less than 12 years of school, had graduated from high school, and had completed at least some college. ■ Consistent with the association of lower educational status and increased risk of chronic disease in the general population, patients with diabetic ESRD had lower educational status on average than did patients with non-diabetic ESRD. **SELF-REPORTED HEALTH STATUS** ■ The health status scores of older and younger patients differed

most in the domain of physical functioning, with older patients scoring lower than younger ones. ■ Diabetic patients tended to report lower health status than non-diabetic patients on generic health status measures, but patients were similar in their ratings of disease-specific health status domains. ■ **Figures 10.2–9** The generic health status domain rated lowest by patients was role-functioning physical, which measures the extent to which physical health interfered with work or other activities during the past four weeks. General health perceptions and energy/fatigue were other generic domains rated more problematic by these patients. ■ **Figures 10.10–17** The disease-specific health status domain rated lowest by patients was burden of kidney disease, which measures the extent to which kidney disease interferes with patients' lives, takes too much of their time, makes them feel frustrated, and/or makes them feel that they are a burden on their families. Sleep and effects of kidney disease on daily life were other disease-specific domains rated more problematic by these patients. **WORK & DISABILITY** ■ **Figure 10.18** Only 37 percent of younger patients and 16 percent of older patients reported at the start of ESRD therapy that they were able to work. Of these patients, only 60 and 40 percent, respectively, were working full- or part-time. Many patients who said they were able to work were thus not actually employed. ■ **Figure 10.21** Patient educational status was consistently related to all work and disability responses. The higher the education level, the more likely the patient was to report being able to work, and, if able, to actually be working. Among patients who said they were unable to work, the reported desire to return to work increased with higher education levels. **REHABILITATION SERVICES** ■ **Figures 10.22–29** Among recipients of physical therapy and cardiac rehabilitation services documented in the 1998–2000 Medicare claims files, two-thirds or more were age 55 or older. ■ At least 65 percent of patients who received physical therapy services had diabetes, stroke, and/or an amputation. Additional research is needed to determine how likely patients with these conditions are to receive physical therapy services. ■ Among recipients of cardiac rehabilitation services there were more men than women, regardless of age. ■ Approximately 75 percent of patients who received cardiac rehabilitation services had a preceding cardiovascular procedure, and about two-thirds of those patients were diabetic, had sustained an AMI, or both. Additional research is needed to determine how likely patients with these conditions are to receive cardiac rehabilitation services.

Maps: National means & patient populations

Figure number	10.24	10.28
Overall value for all pts	13.1	1.56
Total patients	401,456	401,456
Overall value for pts mapped	13.1	1.56
Missing HSA/state: pts dropped	87	87