

Disentangling the Disabling Process: Insights From the Precipitating Events Project

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Among older persons, disability in activities of daily living is common and highly morbid. The Precipitating Events Project (PEP Study), an ongoing longitudinal study of 754 initially nondisabled, community-living persons, aged 70 or older, was designed to further elucidate the epidemiology of disability, with the goal of informing the development of effective interventions to maintain and restore independent function. Over the past 16 years, participants have completed comprehensive, home-based assessments at 18-month intervals and have been interviewed monthly to reassess their functional status and ascertain intervening events, other health care utilization, and deaths. Findings from the PEP Study have demonstrated that the disabling process for many older persons is characterized by multiple and possibly interrelated disability episodes, even over relatively short periods of time, and that disability often results when an intervening event is superimposed upon a vulnerable host. Given the frequency of assessments,

long duration of follow-up, and recent linkage to Medicare data, the PEP Study will continue to be an outstanding platform for disability research in older persons. In addition, as the number of decedents accrues, the PEP Study will increasingly become a valuable resource for investigating symptoms, function, and health care utilization at the end of life.

Key Words: Disability, Epidemiology, Cohort Study, Joseph T. Freeman Lecture

The correlates, causes and consequences of disability are of fundamental concern to a U.S. population whose age structure is shifting dramatically. By 2030, one fifth of the U.S. population will be aged 65 or older; and persons aged 85 or older are the fastest growing segment of the population ([Federal Interagency Forum on Aging-Related Statistics, 2012](#)). Based on annual surveys, about 10% of nondisabled, community-living persons, aged 65 or older, develop disability, defined as the need for personal assistance, in their basic activities of daily living (ADLs) each year ([Katz et al., 1983](#); [Manton, 1988](#)), and an even higher percentage develop

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mobility disability (Guralnik et al., 2000) and disability in their instrumental ADLs (Guralnik & Simonsick, 1993; Jette & Branch, 1981; Katz et al., 1983). Regardless of the type of activity assessed, the prevalence of disability increases with advancing age and is consistently higher among women than men (Guralnik & Ferrucci, 2003). Although the prevalence of disability has declined over the past 30 years, the burgeoning population of older Americans has resulted in little or no change in the absolute number of those with chronic disability (i.e., lasting at least 90 days), which exceeds 7 million (Manton, Gu, & Lamb, 2006).

Disability is associated with increased mortality (Gill, Robison, & Tinetti, 1998; Manton, 1988) and leads to additional adverse outcomes, such as nursing home placement and greater use of formal and informal home services (Coughlin, McBride, Perozek, & Liu, 1992; Katz et al., 1983; Kemper, 1992; Spector, Katz, Murphy, & Fulton, 1987), all of which place a substantial burden on older persons, informal caregivers, and health care resources (Levine, 1999; McKinlay, Crawford, & Tennstedt, 1995; Schulz & Beach, 1999). Over the next 30 years, spending on long-term care for the elderly people is projected to more than double from \$160.7 to \$346.1 billion (Stevenson, 2008). Concurrently, the oldest old support ratio, denoting the number of persons aged 50–74 years (i.e., potential caregivers) divided by the number of those aged 85 or older (i.e., those who need the care), is projected to decline by about 50% (Robine, Michel, & Herrmann, 2007), thereby diminishing the supply of informal caregivers and shifting costs to paid services.

Although several conceptual models of disability have been proposed (Freedman, 2009; Verbrugge & Jette, 1994), one of the most instructive was developed many years ago by the World Health Organization (WHO, 1980). In the WHO model, a disease leads to an impairment, which, in turn, leads to disability. For example, diabetes (disease) leads to poor balance (impairment) secondary to peripheral neuropathy, which then leads to an inability to bathe in the tub/shower (disability). For diabetes and other comparable diseases such as hypertension, the linkage to disability is indirect and often distant, spanning many years to decades. For other chronic diseases, such as knee osteoarthritis, congestive heart failure, chronic obstructive lung disease, and dementia (among others), the linkage is more direct and less distant, spanning many months to years.

As a geriatrician, I have been particularly interested in studying the role of acute (or intervening) illnesses and injuries on the disabling process. Our research has been guided by a “vulnerability” model of disability, which was adapted from prior work on delirium (Inouye & Charpentier, 1996). Our underlying premise is that disability involves a complex interrelationship between baseline vulnerability and intervening events or insults, shown schematically in Figure 1. Older persons who are highly vulnerable (e.g., physically and/or cognitively impaired) may develop disability with any intervening event, even of mild severity (e.g., noninjurious fall or a prolonged upper respiratory infection). Conversely, older persons with low vulnerability will require a noxious insult or severe event (e.g., stroke or a hip fracture) to develop disability.

To test this model of disability and advance the field of disability research, we designed the Precipitating Events Project (otherwise known as the PEP Study), an ongoing longitudinal study of 754 community-living persons age 70 or older. The objectives of this manuscript are to describe the PEP Study and highlight some of its most important findings, focusing primarily on two main areas of research, namely the epidemiology of disability and the role of intervening events on the disabling process.

Precipitating Events Project

Study Population

The assembly of the cohort is summarized in Figure 2 and has been described in detail elsewhere (Gill, Desai, Gahbauer, Holford, & Williams, 2001; Hardy & Gill, 2004). Potential participants were identified from a computerized list of 3,157

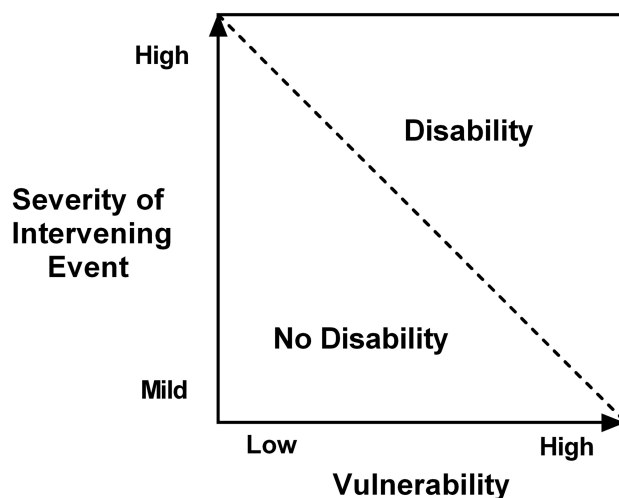


Figure 1. Vulnerability model of disability.

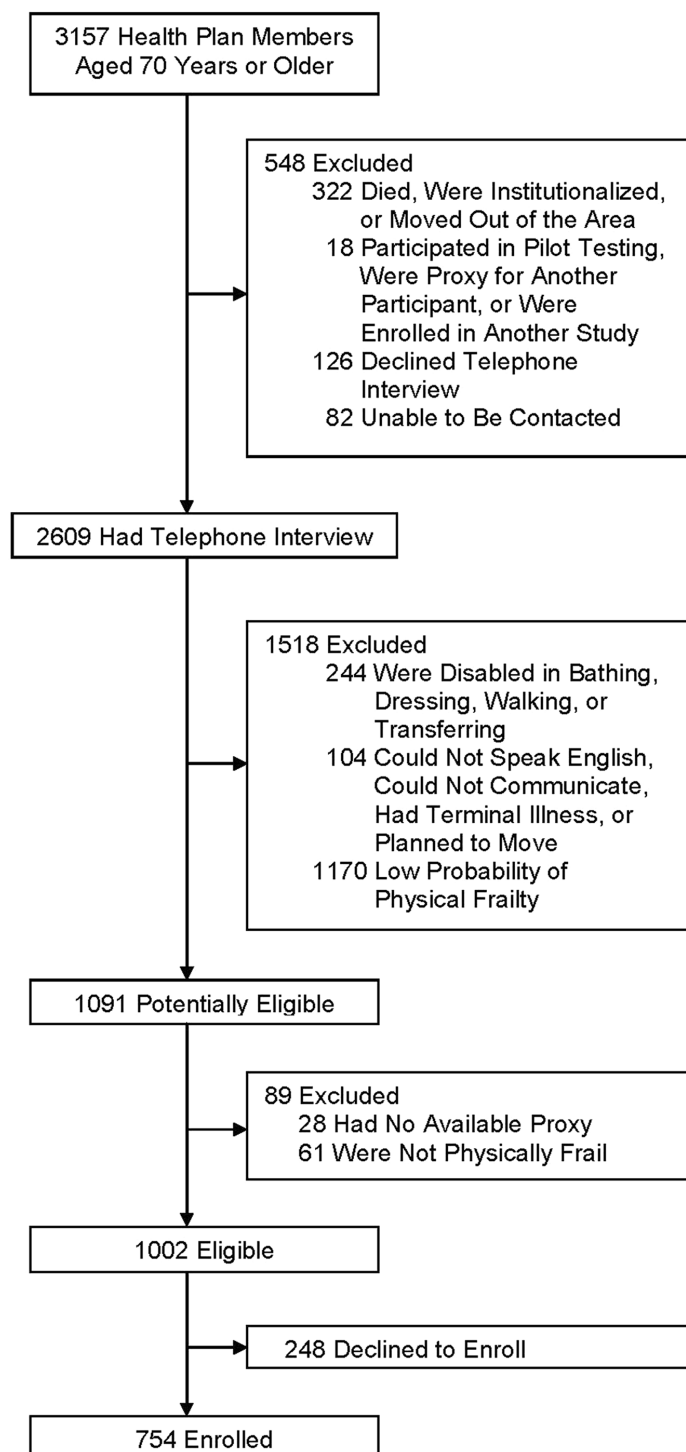


Figure 2. Assembly of the study cohort. Persons who were physically frail were oversampled. After the prespecified number of nonfrail participants were enrolled, potential participants were excluded if they had a low likelihood of physical frailty based on the telephone screen and, subsequently, if they were found not to be physically frail during the in-home assessment.

age-eligible members of a large health plan in greater New Haven, Connecticut. Eligibility was determined during a screening telephone interview and was confirmed during an in-home assessment. Members were potentially eligible if they were nondisabled (i.e., required no personal assistance) in four basic ADLs—bathing, dressing, walking

inside the house, and transferring from a chair. Exclusion criteria included significant cognitive impairment with no available proxy, inability to speak English, diagnosis of a terminal illness, and a plan to move out of the area during the next year.

Based on our initial sample size calculations, persons were oversampled if they were physically frail,

as denoted by a timed score greater than 10 s on the rapid gait test (i.e., walk back and forth over a 10-ft [3-m] course as quickly as possible; (Gill, Williams, & Tinetti, 1995). In the absence of a gold standard, operationalizing physical frailty as slow gait speed was justified by its high face validity (Goodwin, 2002), clinical feasibility (Gill, McGloin, Gahbauer, Shepard, & Bianco, 2001), and strong epidemiologic link to functional decline and disability (Abellan van Kan et al., 2009; Gill et al., 1995; Guralnik, 1994). Only 4.6% of the 2,753 health plan members who were alive and could be contacted refused to complete the screening telephone interview, and 75.2% of the eligible members agreed to participate and were enrolled between March 1998 and October 1999. Persons who refused to participate did not differ significantly from those who were enrolled in terms of age or sex. The study protocol was approved by the Yale Human Investigation Committee, and all participants provided verbal informed consent.

Data Collection

Comprehensive home-based assessments have been completed at 18-month intervals (except at 126 months), and telephone interviews have been completed monthly. For participants who have significant cognitive impairment or are otherwise unavailable, a proxy is interviewed using a rigorous protocol, with demonstrated reliability and validity (Gill, Hardy, & Williams, 2002).

Comprehensive Assessments.—The core elements, included at each time point, are provided in Table 1. Height and other demographic information, such as education, were ascertained at baseline only. The nine self-reported, physician-diagnosed chronic conditions include hypertension, myocardial infarction, congestive heart failure, stroke, diabetes mellitus, arthritis, hip fracture, chronic lung disease, and cancer. Based on prior work, which found that questions about difficulty and dependence provide complementary information

Table 1. Core Elements of the Comprehensive Home-Based Assessments

Element	Evaluation protocol and relevant details
Demographics, smoking	Marital status, household composition, housing type
Chronic conditions, medications	Interview, recorded from pill bottles
Self-rated health, health care utilization	Interview
Body mass index, weight loss	Interview
Cognition	MMSE ^a
Physical capability	Battery of timed and qualitative tests of physical performance ^b
Basic and instrumental activities	Modified OARS Functional Assessment Questionnaire ^c
Mobility	Walk a quarter mile, climb flight of stairs, lift/carry 10 lb, time walked per day ^d
Physical activity level	PASE ^e
Social activity level	Adapted from EPESE interview ^f
Functional self-efficacy	Modified ADL Efficacy Scale ^g
Depressive symptoms	CES-D (11-item version) ^h
Social support	Modified version of MOS Social Support Survey ⁱ
Vision, hearing	Jaeger card, Audioscope ^j
Muscle and grip strength	Hand-held Chatillon 100 dynamometer ^k
Peak expiratory flow rate	Hand-held spirometer ^l

^aMMSE: Mini-Mental State Examination (Folstein, Folstein, & McHugh, 1975).

^bDescribed in Gill et al. (2012); Gill et al., (1995); Marottoli et al., (1998); Mathiowetz, Weber, Kashman, & Volland, (1985).

^cOARS: Older Americans' Resources and Services (Fillenbaum & Smyer, 1981; Gill, Allore, et al., 2003; Gill, Allore, & Guo, 2004).

^dDescribed in Gill, Allore, & Guo, (2004).

^ePASE: Physical Activity Scale for the Elderly (Washburn, Smith, Jette, & Janney, 1993).

^fEPESE: Established Populations for Epidemiologic Studies of the Elderly (Cornoni-Huntley et al., 1993).

^gADL: Activities of Daily Living (Tinetti, Mendes de Leon, Doucette, & Baker, 1994).

^hCES-D: Center for Epidemiologic Studies Depression scale (Kohout, Berkman, Evans, & Cornoni-Huntley, 1993).

ⁱMOS: Medical Outcomes Study (Sherbourne & Stewart, 1991).

^jDescribed in Lichtenstein, Bess, & Logan (1988); Spaeth, Fralick, & Hughes (1955).

^kDescribed in Gill, Gahbauer, et al. (2006); Gill et al. (2009).

^lDescribed in Vaz Fragoso, Gahbauer, Van Ness, & Gill (2007).

(Gill et al., 1998), questions about both difficulty and dependence have been included for each of the seven basic activities (bathing, dressing, transferring, walking, eating, toileting, and grooming), five instrumental activities (shopping, housework, meal preparation, taking medications, and managing finances), and three mobility tasks (walk a quarter mile, climb flight of stairs, and lift/carry 10 pounds). A fourth mobility item, also scored as 0, 1, or 2, was based on the average amount of time (in hours) walked per day (>0.75 , 0.25 – 0.75 , or <0.25 ; Gill, Allore, & Guo, 2004). To enhance the quality of the data, the need for a proxy informant is evaluated during each comprehensive assessment. From the available data, slightly modified versions of the Fried Frailty Phenotype (Gill, Gahbauer, Allore, & Han, 2006) and Short Physical Performance Battery (Gill, Murphy, Barry, & Allore, 2009) have been developed. In addition, expanded modules on bathing (Naik, Concato, & Gill, 2004; Naik & Gill, 2005), sleep (Vaz Fragoso, Gahbauer, Van Ness, & Gill, 2009), and fatigue (Yellen, Cella, Webster, Blendowski, & Kaplan, 1997) were added to the comprehensive assessments starting at 36, 90, and 108 months, respectively; and age stereotypes (Levy, Slade, & Gill, 2006; Levy, Slade, Murphy, & Gill, 2012) were assessed at baseline and 108 months. With few exceptions, data on the core elements were 100% complete at baseline and greater than 95% complete during the subsequent comprehensive assessments. To account for these missing data, we have used sequential Markov Chain Monte Carlo imputation for multivariate normal data.

Monthly Interviews.—With the support of a computer-aided telephone interview, participants are

interviewed monthly to ascertain their exposure to intervening events, monitor their health care utilization, and reassess their functional status. The intervening events include illnesses and injuries leading to either hospitalization or restricted activity (Gill, Allore, Holford, & Guo, 2004b). Participants are asked whether they had stayed at least overnight in a hospital since the last interview, that is, during the past month. To ascertain less potent intervening events, participants are asked two questions related to restricted activity: (a) “Since we last talked on (date of last interview), have you cut down on your usual activities due to an illness, injury or other problem?” and (b) “Since we last talked on (date of last interview), have you stayed in bed for at least half a day due to an illness, injury or other problem?” Participants are considered to have restricted activity if they answered “Yes” to one or both of the questions. If participants have restricted activity, they are asked sequentially whether they have had any of 24 prespecified problems (Table 2) “since we last talked on (date of last interview).”

Participants who have been hospitalized are asked the name of the hospital and the primary reason for their admission. These reasons are subsequently grouped into distinct diagnostic categories using a revised version of the protocol described by Ferrucci and coworkers (Ferrucci, Guralnik, Pahor, Corti, & Havlik, 1997; Gill, Allore, et al., 2004b). Participants are also asked whether they had seen a doctor in the office or an emergency room since their last interview and the primary reason for these visits. An additional set of questions asks specifically about seeing a psychiatrist, psychologist, or counselor, and about admissions to a nursing home (or hospice) since the last interview (Gill, Allore, & Han, 2006).

Table 2. Potential Problems Leading to Restricted Activity

1) Pain or stiffness in your joints	15) Nausea, vomiting, diarrhea, or other stomach (abdominal) problem
2) Pain or stiffness in your back	16) A problem with your memory or difficulty thinking
3) Leg pain on walking	17) Been depressed
4) Weakness of your arms or legs	18) Been anxious or worried
5) Swelling in your feet or ankles	19) Frequent or painful urination
6) Been fatigued (no energy/very tired)	20) Lost control of your urine and wet yourself
7) Difficulty breathing or shortness of breath	21) Has a family member or friend become seriously ill or had an accident
8) Chest pain or tightness	22) Experienced the death or loss of a family member or friend
9) Poor or decreased vision	
10) Been dizzy or unsteady on your feet	23) A change in your medications
11) A fall or injury	24) A problem with alcohol
12) Been afraid of falling	25) Other reason(s) for restricted activity
13) Cold or flu symptoms	
14) Difficulty with sleeping	

Finally, participants are asked, “At the present time, do you need help from another person to (complete the task)?” for each of four basic activities (bathing, dressing, walking inside the house, and transferring from a chair), five instrumental activities (shopping, housework, meal preparation, taking medications, and managing finances), and three mobility activities (walk $\frac{1}{4}$ mile, climb flight of stairs, and lift/carry 10 pounds). For these 12 activities, disability is operationalized as the need for personal assistance (Gill, Murphy, Gahbauer, & Allore, 2013a). Participants are also asked about a fourth mobility activity, “Have you driven a car during the past month?” Participants who respond “No” are deemed to have stopped driving. To maintain consistency with the other activities, these participants are classified as being “disabled” in driving that month (Gill, Gahbauer, Murphy, Han, & Allore, 2012).

In accordance with recommendations for binary longitudinal data (Wang & Fitzmaurice, 2006), we have used multiple imputation to address the small amount of missing monthly data on functional status (Gill, Guo, & Allore, 2008). Missing data have not been imputed for the intervening events.

Hospital Records.—For all self-reported hospital admissions, we obtain discharge summaries and extract information, using standard procedures (Inouye et al., 1998), on dates of admission and discharge, diagnosis on admission, primary and other (up to 16) diagnoses at discharge (with International Classification of Diseases, Ninth Revision [ICD]-9 codes), major procedures (≤ 12 with ICD-9 codes), expected source of payment (e.g., Medicare and Medicaid), and discharge location (e.g., home and nursing home). Although our ultimate goal is to obtain and review such records for all admissions, for efficiency in the context of an ongoing longitudinal study, we have focused our efforts to date primarily on decedents because they can have no additional hospital admissions.

Deaths.—Deaths are ascertained from local obituaries and/or an informant during a subsequent interview. From the informant, we obtain information on date of death, hospitalization since the last interview, reason for the hospitalization, nursing home (or hospice) admission since the last interview, site and cause of death, whether the death was expected versus sudden/unexpected, and the need for (and duration of) personal assistance with

the 12 basic, instrumental, and mobility activities during the last year of life. In addition, we obtain a copy of the death certificate and have a certified nosologist provide us with the ICD-10 codes for the immediate and underlying causes of death (Gill, Gahbauer, Han, & Allore, 2010).

Medicare Data.—In 2011, we obtained detailed participant-level data on health care utilization (from 1997 forward) through linkages with Medicare claims, using procedures adapted from prior studies (Wolinsky et al., 2007). These claims are based on the information needed to process and pay bills for persons insured by Medicare. The Medicare denominator file (1998), Beneficiary Summary File (up to 2009), and Master Beneficiary Summary File (after 2009) contain monthly managed care indicators (yes/no), denoting whether the beneficiary is in Medicare Fee-For-Service (FFS) or managed care (Part C). Monthly entitlement indicators, denoting Parts A, B, and D, are also provided. Claims are divided into files based on billing form and location of care (inpatient hospital, outpatient, skilled nursing facility, hospice, home health; Centers for Medicare & Medicaid Services, 2014). More recently, we have obtained files on durable medical equipment and assessment data from the Long-Term Care Minimum Data Set (MDS), available for all participants who are in Medicare or Medicaid nursing facilities (Rahman & Applebaum, 2009) and from the Home Health Outcome and Assessment Information Set, available for participants receiving Medicare-supported home care services (Fortinsky, Garcia, Joseph Sheehan, Madigan, & Tullai-McGuinness, 2003). Updates of these files are obtained annually.

A successful match to Medicare claims has been made for all but one of the 754 participants. Because the participants were originally members of a large health plan, nearly half (49.9%) were in managed Medicare during at least part of the follow-up period, with an overall mean (*SD*) penetrance (per 100 person-month) of 23.0 (12.3). This value has ranged from a high of 46.0 in 1999 to a low of 12.1 in 2004. MDS assessment data and claims for hospice care are included in the files regardless of plan type, that, FFS or managed care.

Findings

Through December 2013, 593 (78.6%) participants have died after a median of 93 months, whereas 43 (5.7%) have dropped out of the study

Table 3. Characteristics of Participants Over Time^a

Characteristic	Baseline, N = 754	18 months, N = 681	36 months, N = 626	54 months, N = 558	72 months, N = 493	90 months, N = 440	108 months, N = 378	144 months, N = 245	162 months, N = 195
Demographic									
Age (years), <i>M</i> ± <i>SD</i>	78.4 ± 5.3	79.7 ± 5.1	81.0 ± 5.1	82.2 ± 4.9	83.8 ± 4.9	84.9 ± 4.7	86.1 ± 4.6	88.2 ± 4.3	89.4 ± 4.0
Female sex, <i>n</i> (%)	487 (64.6)	444 (65.2)	415 (66.3)	377 (67.6)	327 (66.3)	298 (67.7)	262 (69.3)	168 (68.6)	135 (69.2)
Non-Hispanic white ethnicity, <i>n</i> (%)	682 (90.5)	615 (90.3)	562 (89.8)	501 (89.8)	441 (89.5)	391 (88.9)	337 (89.2)	218 (89.0)	171 (87.7)
Education (years), <i>M</i> ± <i>SD</i>	12.0 ± 2.9	12.0 ± 2.9	12.0 ± 2.8	12.0 ± 2.9	12.0 ± 2.9	12.0 ± 2.9	12.0 ± 2.9	12.1 ± 2.8	12.1 ± 2.7
Currently married, <i>n</i> (%)	361 (47.9)	300 (44.1)	270 (43.1)	232 (41.6)	193 (39.2)	159 (36.2)	124 (32.8)	66 (27.1)	46 (23.6)
Living alone, <i>n</i> (%)	298 (39.5)	277 (40.7)	253 (40.4)	210 (37.6)	193 (39.2)	177 (40.2)	149 (39.4)	93 (38.0)	69 (35.4)
Nursing home resident, <i>n</i> (%)	0 (0)	12 (1.8)	27 (4.3)	44 (7.9)	50 (10.1)	53 (12.1)	62 (16.5)	40 (16.3)	33 (16.9)
Health related									
No. chronic conditions, <i>M</i> ± <i>SD</i>	1.8 ± 1.2	1.9 ± 1.3	2.1 ± 1.3	2.1 ± 1.3	2.3 ± 1.3	2.3 ± 1.3	2.5 ± 1.3	2.7 ± 1.4	2.8 ± 1.4
No. prescription medications, <i>M</i> ± <i>SD</i>	4.0 ± 2.4	4.6 ± 2.6	5.2 ± 2.7	5.4 ± 2.7	5.8 ± 2.9	6.2 ± 3.0	6.4 ± 3.1	7.0 ± 3.2	6.7 ± 3.3
Severe hearing impairment, ^b <i>n</i> (%)	163 (21.6)	193 (28.3)	178 (28.4)	186 (33.3)	178 (36.1)	188 (42.7)	163 (43.1)	128 (52.2)	92 (47.2)
Severe visual impairment, ^c <i>n</i> (%)	133 (17.6)	164 (24.1)	142 (22.7)	141 (25.3)	142 (28.8)	155 (35.2)	141 (37.3)	87 (35.5)	72 (36.9)
Weight loss ≥ 4.5 kg in past year, <i>n</i> (%)	175 (23.2)	122 (17.8)	135 (21.6)	113 (20.3)	118 (23.9)	103 (23.4)	103 (27.3)	63 (25.7)	62 (31.8)
Frailty, ^d <i>n</i> (%)	194 (25.7)	218 (32.0)	232 (37.1)	228 (40.9)	230 (46.7)	216 (49.1)	208 (55.0)	159 (64.9)	132 (67.7)
Self-rated health (0 – 5), <i>M</i> ± <i>SD</i>	3.0 ± 0.9	3.1 ± 0.9	3.1 ± 1.0	3.0 ± 1.0	3.1 ± 0.9	3.0 ± 1.0	3.0 ± 1.0	3.0 ± 0.9	2.9 ± 1.0
Disability^e									
Basic activities (0 – 14), <i>M</i> ± <i>SD</i>	0.4 ± 1.0	1.1 ± 2.2	1.8 ± 2.9	2.0 ± 3.3	3.0 ± 4.2	3.5 ± 4.5	4.0 ± 5.0	4.4 ± 4.9	5.1 ± 5.1
Instrumental activities (0 – 10), <i>M</i> ± <i>SD</i>	1.6 ± 2.4	3.3 ± 3.2	4.0 ± 3.5	3.8 ± 3.7	4.7 ± 3.8	5.0 ± 3.8	5.5 ± 3.8	6.1 ± 3.8	6.6 ± 3.6
Mobility activities, (0 – 8), <i>M</i> ± <i>SD</i>	2.2 ± 1.7	2.7 ± 2.0	3.3 ± 2.0	3.4 ± 2.1	4.0 ± 2.3	4.2 ± 2.4	4.5 ± 2.5	4.8 ± 2.4	5.2 ± 2.3
Cognitive or psychosocial									
MMSE score < 24, <i>n</i> (%)	86 (11.4)	104 (15.3)	100 (16.0)	120 (21.5)	121 (24.5)	109 (24.8)	119 (31.5)	79 (32.2)	76 (39.0)
CES-D score ≥ 20, <i>n</i> (%)	100 (13.3)	120 (17.6)	132 (21.1)	114 (20.4)	97 (19.7)	106 (24.1)	85 (22.5)	52 (21.2)	51 (26.2)
Low functional self-efficacy ^f , <i>n</i> (%)	241 (32.0)	229 (33.6)	259 (41.4)	253 (45.3)	261 (52.9)	248 (56.4)	225 (59.5)	156 (63.7)	130 (66.7)
Low social support ^g , <i>n</i> (%)	167 (22.2)	161 (23.6)	128 (20.5)	105 (18.8)	126 (25.6)	117 (26.6)	102 (27.0)	55 (22.5)	46 (23.6)
Social activities (0 – 20), <i>M</i> ± <i>SD</i>	8.5 (3.3)	7.8 (3.3)	7.7 (3.5)	6.9 (3.5)	6.6 (3.6)	6.5 (3.6)	6.0 (3.7)	6.2 (3.5)	5.9 (3.5)

(Table continues on next page)

Table 3. (Continued)

Characteristic	Baseline, N = 754	18 months, N = 681	36 months, N = 626	54 months, N = 558	72 months, N = 493	90 months, N = 440	108 months, N = 378	144 months, N = 245	162 months, N = 195
Behavioral									
Current smoker, <i>n</i> (%)	63 (8.4)	48 (7.1)	41 (6.6)	27 (4.8)	23 (4.7)	22 (5.0)	12 (3.2)	5 (2.0)	1 (0.5)
Low physical activity, ^h <i>n</i> (%)	232 (30.8)	266 (39.1)	303 (48.7)	291 (52.2)	274 (55.6)	264 (60.0)	240 (63.5)	180 (73.5)	154 (79.0)
Body mass index $\geq 30 \text{ kg/m}^2$, <i>n</i> (%)	165 (21.9)	154 (22.6)	141 (22.5)	117 (21.0)	93 (18.9)	82 (18.6)	70 (18.5)	47 (19.2)	37 (19.0)
Physical capacity									
Slow gait speed, ⁱ <i>n</i> (%)	322 (42.7)	293 (43.0)	279 (44.6)	284 (50.9)	279 (56.6)	254 (57.7)	243 (64.3)	168 (68.6)	146 (74.9)
SPPB score, <i>M</i> \pm <i>SD</i>	6.8 \pm 2.9	6.8 \pm 2.9	6.5 \pm 3.0	5.8 \pm 3.1	5.2 \pm 3.1	5.1 \pm 3.3	4.4 \pm 3.2	3.4 \pm 3.0	3.2 \pm 3.2
Low grip strength, ^j <i>n</i> (%)	407 (54.0)	439 (64.5)	378 (60.4)	387 (69.4)	330 (66.9)	303 (68.9)	263 (69.6)	222 (90.6)	153 (78.5)
Low peak expiratory flow, ^k <i>n</i> (%)	175 (23.2)	147 (21.6)	143 (22.8)	143 (25.6)	194 (39.4)	169 (38.4)	137 (36.2)	73 (29.8)	61 (31.3)

Note: CES-D, Center for Epidemiological Studies-Depression scale; MMSE, Mini-Mental State Examination; MMSE, Mini-Mental State Examination; SPPB, Short Physical Performance Battery.

^aA comprehensive assessment was not completed at 126 months.

^bMissed four of four tones based on 1000 and 2000 HZ measurements for the left and right ears.

^cValue $> 26\%$ as assessed with a Jaeger card.

^dMet three or more of the five criteria from the Fried phenotype.

^eActivities were scored as "0" for no personal help and no difficulty, "1" for difficulty but no help, and "2" for help. A fourth mobility item, also scored as 0, 1, or 2, was based on the average amount of time (in hours) walked per day (>0.75 , 0.25 – 0.75 , or <0.25 ; Gill, Allore, & Guo, 2004).

^fScore ≤ 27 , denoting worst quartile based on the first 356 enrolled participants who had been selected randomly from the source population.

^gScore ≤ 18 on Medical Outcomes Study (MOS) Social Support scale.

^hScore < 64 for men and < 52 for women on Physical Activity Scale for the Elderly (PASE).

ⁱTime > 10 s to walk back and forth over a 10-ft (3-m) course as quickly as possible.

^jValue less than or equal to the gender- and body mass index-specific cut-points provided by Fried et al. (2001).

^kValue $< 10\%$ of the standardized residual percentile (Vaz Fragoso, Gahbauer, Van Ness, Concato, & Gill, 2008).

after a median of 27 months. Data are otherwise available for 99.2% of the 79,451 monthly interviews. Completion of the comprehensive assessments has ranged from 92.0% at 162 months to 96.2% at 18 months. The characteristics of the participants over time are provided in Table 3. About two thirds are women, and 1 out of 10 are non-Hispanic white. As the cohort has aged, nearly all health-related, disability, cognitive, psychosocial, and physical capacity characteristics have worsened. Over time, an increasing percentage of participants have been nursing home residents and have had low levels of physical activity. Self-rated health, in contrast, has been remarkably stable.

A complete listing of the original reports from the PEP Study is provided in the [Supplementary Material](#). We focus herein on two areas that have been the major thrust of research: epidemiology of disability and role of intervening events in the disabling process.

Epidemiology of Disability

Our understanding of the disabling process has largely been based on the results of longitudinal studies that have had long intervals between assessments of functional status, ranging from 6 months to 6 years. Although disability in older persons is often thought to be progressive or permanent, prior research has shown that it is a dynamic process, with individuals moving in and out of states of disability (Verbrugge, Reoma, & Gruber-Baldini, 1994). Indeed, recovery rates as high as 28% have been demonstrated in previous longitudinal studies of community-living older persons that included assessment intervals of 12–24 months (Gill, Robison, & Tinetti, 1997; Katz et al., 1983; Manton, 1988). The premise underlying our research is that disability among older persons is a complex and highly dynamic process with considerable heterogeneity and multiple potential pathways.

Disability has been Substantially Underestimated by Previous Studies.—When ascertaining the occurrence of disability, long assessment intervals may be problematic because they do not account for the possibility of recovery nor for deaths or losses to follow-up. Using data from our monthly interviews, we compared the rates of disability obtained from single follow-up assessments with those obtained from monthly assessments for intervals up to 24 months (Gill, Hardy,

et al., 2002). We found that the rates of disability obtained from monthly assessments (i.e., cumulative disability) were considerably greater than those obtained from single follow-up assessments (i.e., prevalent disability) and that these differences in rates increased progressively as the length of the assessment interval increased. For example, the cumulative and prevalence rates of disability in participants (at intermediate risk) were 0.24 and 0.11 at 6 months, 0.36 and 0.20 at 12 months, 0.46 and 0.16 at 18 months, and 0.53 and 0.20 at 24 months, respectively. Although these differences in rates were attributable almost exclusively to recovery from disability in the first 6 months, they were due increasingly to deaths and losses to follow-up over the next 18 months, particularly among participants at high risk for disability. These findings suggest that more frequent assessments of functional status could lead to an improved understanding of the course and overall burden of disability among older persons.

Newly Disabled Elders Have High Rates of Recovery.—To set realistic goals and plan for appropriate care, disabled older persons, along with their families and clinicians, need accurate information about the likelihood and time course of recovery. The objectives of this study were to determine the rate of and time to recovery of independent function in community-living older persons who had become newly disabled in their basic ADLs, to determine the duration of recovery, and to compare the likelihood of recovery among pertinent subgroups of older persons (Hardy & Gill, 2004). During a median follow-up of 51 months, 420 (56%) participants experienced at least one episode of disability. Of these participants, 399 (81%) recovered (i.e., regained independence in all four ADLs) within 12 months of their initial disability episode, and a majority (57%) of these maintained independence for at least 6 months. Among participants who experienced three or more consecutive months of disability, a majority (60%) recovered, but only a third of these maintained independence for at least 6 months. Persons who were cognitively impaired, physically frail, or severely disabled (i.e., in 3–4 ADLs) at onset were less likely to recover than those who were cognitively intact, nonfrail, or mildly disabled, respectively. Nonetheless, a majority of participants within each subgroup recovered. These results suggest that recovery from disability among older persons is much more common than previous studies

have indicated but is often transient. Although most newly disabled older persons can be reassured that they will regain independent function, those who recover are at high risk for recurrent disability. Subsequent studies that have included multiple follow-up assessments have also documented recovery rates higher than those that had been previously reported and demonstrated high rates of recurrent disability and functional decline (Boyd et al., 2008, 2009; Prvu Bettger, Coster, Latham, & Keysor, 2008).

The frequency of our assessments enabled us to ascertain brief episodes of disability that are disproportionately missed in longitudinal studies with assessment intervals of 6–24 months, likely accounting for our higher recovery rates. More than half of the initial disability episodes in our study population lasted only 1 or 2 months. Although the clinical relevance of short-term disability has been questioned (Guralnik & Ferrucci, 2002), we have shown that disability lasting only 1 or 2 months is strongly associated with the development of future disability and death (Gill & Kurland, 2003). In a subsequent study (Hardy & Gill, 2005), we found that habitual physical activity was associated with shorter time to recovery and longer duration of recovery, lending support to efforts designed to promote physical activity among vulnerable older persons (Fielding et al., 2011; Life Study Investigators et al., 2006).

Multistate Model of Disability.—The disabling process can be conceptualized as a series of transitions between states of disability and independence, as shown in Figure 3. Although prior studies of disability have evaluated multiple transitions over time (Beckett et al., 1996; Mendes de Leon et al., 1999), relatively little is known about the frequency and patterns of these transitions for

individual persons. In addition, because prior studies have largely used assessment intervals of 12 months or longer, they have likely missed clinically meaningful transitions between disability states. In a study having a median follow-up of 5 years, we found that half of non-physically frail older persons and 20% of their frail counterparts remained independent and, therefore, made no transitions (Hardy, Dubin, Holford, & Gill, 2005). Among participants with at least one transition, the median numbers of transitions were three and six for the nonfrail and frail participants, respectively. The range in number of transitions was very large, suggesting substantial variation among individuals for risk of disability transitions, even within subgroups classified by frailty. Although both nonfrail and frail participants spent the majority of time in the non-disabled state, frail participants had higher rates of transitions to states of greater disability, lower rates of transitions to states of lesser or no disability, and lower rates of transitions from severe disability to death. These findings provide support for the postulate of Campbell and Buchner that a key consequence of frailty is unstable disability, in which persons experience substantial fluctuations in function in the setting of minor external events (Campbell & Buchner, 1997).

In subsequent studies, we have used the multistate model to evaluate gender differences in disability, to investigate the role of depressive symptoms, a potentially modifiable risk factor, on the disabling process, and to determine the effect of prior disability history on subsequent functional transitions. We found that the higher prevalence of disability in older women, compared with men, is attributable to both a higher incidence and a longer duration of disability, resulting from lower rates of recovery and death among disabled older

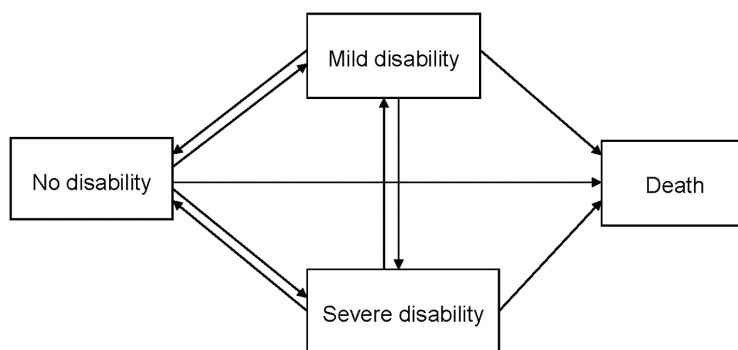


Figure 3. A multistate model of disability. Boxes represent the four states, and arrows represent the possible transitions between states. No disability is defined as the ability to perform all four basic activities of daily living (ADLs) without personal assistance. Mild disability is defined as disability in one or two ADLs. Severe disability is defined as disability in three or four ADLs.

women (Hardy, Allore, Guo, & Gill, 2008). We also found that clinically significant depressive symptoms, defined as a score of 20 or greater on the Center for Epidemiologic Studies-Depression (CES-D) scale, are associated with transitions into and out of disability states (Barry, Murphy, & Gill, 2011). Specifically, participants with depressive symptoms were more likely than those who were nondepressed to develop both mild and severe disability and to become more severely disabled in the setting of mild disability, and were less likely to recover independent function in the setting of both mild and severe disability. Hence, depressive symptoms act not only to make one vulnerable to developing disability but also to impede recovery from disability and to increase the likelihood of disability progression.

Finally, we found that both the cumulative duration of prior disability and the number of prior episodes of disability are independently associated with subsequent functional transitions (Hardy, Allore, Guo, Dubin, & Gill, 2006). Specifically, more months of prior disability are associated with a higher likelihood of new or worsening disability and a lower likelihood of regaining independence, and more episodes of prior disability are associated with a higher likelihood of most transitions, representing both increasing and decreasing disability. Most previous research evaluating multiple functional transitions has used methods such as Markov models, which assume no effect of prior disability history on subsequent functional transitions (Beckett et al., 1996; Mendes de Leon et al., 1997, 1999). Based on our findings, such models are not appropriate when evaluating transitions in disability over time.

Trajectories of Disability in Last Year of Life.—

Despite the importance of functional status to older persons and their families, relatively little is known about the course of disability at the end of life. In this study (Gill, Gahbauer, et al., 2010), 383 PEP participants who had died over the course of 10.5 years were evaluated for disability in their basic ADLs. We identified five distinct trajectories of disability in the last year of life, from least disabled to most disabled: 65 participants had no disability (17.0%); 76 had catastrophic disability (19.8%), characterized by the sudden onset of disability in the last few months of life; 67 had accelerated disability (17.5%), characterized by the onset and gradual worsening of disability starting about

10 months before their death; 91 had progressive disability (23.8%), characterized by worsening disability during the entire year prior to their death; and 84 had persistently severe disability (21.9%) throughout the last year of their life. The most common condition leading to death was frailty (27.9%), followed by organ (e.g., heart, lung, and kidney) failure (21.4%), cancer (19.3%), other causes (14.9%), advanced dementia (13.8%), and sudden death (2.6%). When the distribution of the disability trajectories was evaluated according to mode of death, a predominant trajectory was observed only for advanced dementia (persistently severe disability [67.9%]) and sudden death (nondisabled [50.0%]). For the four other modes of death, the percentages did not exceed 34 for any of the disability trajectories. One out of five participants who died from cancer were nondisabled throughout the last year of life, compared with only 12.2% and 14.0% of those in the organ failure and frailty groups, respectively. These results suggest that the need for services at the end of life to assist with basic ADLs is at least as great for older persons dying from organ failure and frailty as for those dying from a more traditional terminal condition such as cancer and is much greater for older persons dying from advanced dementia. Nonetheless, the absence of a predictable disability trajectory based on mode of death for most decedents poses significant challenges for the proper allocation of resources to care for older persons at the end of life.

Role of Intervening Events in the Disabling Process

An important impediment to the development of preventive interventions is an incomplete understanding of the mechanisms underlying the disabling process (Ebrahim, 1999; Landefeld & Chren, 1998). Previous epidemiological studies have focused almost exclusively on identifying vulnerable older persons at risk for disability (Stuck et al., 1999). Relatively little is known, in contrast, about the role of intervening events that precipitate disability. We have focused our research on intervening illnesses and injuries leading to hospitalization and restricted activity, respectively.

Hospitalization.—In the first of two studies (Gill, Allore, et al., 2004b), we followed participants with monthly telephone interviews for up to 5 years to ascertain exposure to hospitalizations and determine the onset of new disability in basic ADLs. We

found that the multivariable hazard ratio [HR] for the development of disability was 61.8 (95% confidence interval [CI], 49.0–78.0) within a month of hospitalization. The corresponding HR for disability with nursing home admission immediately following hospitalization was 223 (95% CI, 138–362). The population-attributable fractions associated with new exposure to hospitalization were 0.48 for any disability and 0.82 for disability with nursing home admission. Although cardiac (coronary heart disease, congestive heart failure, arrhythmia, and so forth) was the most common diagnostic category for hospitalization, fall-related injury conferred the highest risk of disability, with 79.4% of admissions for a fall-related injury leading to any disability and 58.8% to disability with nursing home admission.

In the second study (Gill, Allore, Gahbauer, & Murphy, 2010), we evaluated the effect of hospitalizations on the functional transitions shown in Figure 3. Only 117 (15.5%) participants remained nondisabled and alive through the end of the 10.5-year follow-up period. We found that illnesses and injuries leading to hospitalization were associated with worsening functional ability for nearly all transitions between states of no disability, mild disability, severe disability and death, with HRs as high as 168 (95% CI, 118–239) for the transition from no disability to severe disability and as low as 0.41 (95% CI, 0.30–0.54) for the transition from mild disability to no disability. Regardless of sex or age, the absolute risks for new or worsening disability or death were greatest for participants who were physically frail and hospitalized, with probabilities as high as 20.0% (95% CI, 19.6%–20.3%) for the transition from no disability to mild disability among women aged 85 or older. Among the possible reasons for hospitalization, fall-related injuries conferred the highest likelihood for developing new or worsening disability.

The results from concurrent and subsequent studies have further underscored the deleterious effects of hospitalization on the onset and progression of disability in older persons (Boyd, Xue, Guralnik, & Fried, 2005; Boyd, Xue, Simpson, Guralnik, & Fried, 2005; Davydow, Hough, Levine, Langa, & Iwashyna, 2013), as nicely summarized by a recent monograph on hospitalization-associated disability (Covinsky, Pierluissi, & Johnston, 2011).

Restricted Activity.—In a prior study (Gill, Williams, & Tinetti, 1999), which included annual

assessments, we found that about half of non-disabled older persons who developed disability did not have an acute hospitalization during the 1-year follow-up period, suggesting that disability may often be precipitated by less severe illnesses or injuries that do not lead to hospitalization. In the PEP Study, restricted activity has served as the minimum threshold for identifying these potentially important events. During a median follow-up of 15 months, we found that about three of four participants reported restricted activity during at least one month, and about 40% reported restricted activity during two consecutive months (Gill, Desai, et al., 2001). The rate of restricted activity per 100 person-months was 19.0. Among 24 pre-specified health- and nonhealth-related problems, the rates per 100 person-months of restricted activity ranged from 0.1 for “problem with alcohol” to 65.5 for “been fatigued.”

In subsequent studies, we have shown that these episodes of restricted activity are important sources of disability and functional decline (Gill, Allore, et al., 2004b, 2010; Gill, Allore, & Guo, 2003). Specifically, the likelihood of developing disability within a month of restricted activity was elevated more than fivefold (Gill, Allore, et al., 2004b). The population-attributable fraction associated with new exposure to restricted activity was 0.19 for any disability, but only 0.05 for disability with nursing home admission. In the context of our multistate model, we have found that restricted activity also increases the likelihood of transitioning from no disability to both mild and severe disability (HR, 2.59; 95% CI, 2.23–3.02 and HR, 8.03; 95% CI, 5.28–12.21), respectively, and from mild disability to severe disability (HR, 1.45; 95% CI, 1.14–1.84), but is not associated with recovery from mild or severe disability (Gill, Allore, et al., 2010). Of all the reasons for restricted activity, a fall or injury conferred the highest likelihood of transitioning from no disability to mild or severe disability, respectively, and the second highest likelihood (after problem with memory or difficulty thinking) of transitioning from mild disability to severe disability.

Insidious Disability.—To further test our vulnerability model (Figure 1), we evaluated how often disability in basic ADLs develops insidiously, that is, in the absence of a hospitalization and restricted activity, and to determine whether the likelihood of insidious disability differs on the basis of physical frailty (Gill, Allore, Holford, & Guo, 2004a).

For first episodes of disability, we found that 73 of 203 (36%) developed insidiously among the 322 participants who were physically frail, and 26 of 141 (18%) developed insidiously among the 432 participants who were not physically frail ($p < .001$). Physical frailty was the only factor that was significantly associated with the development of insidious disability, with an adjusted odds ratio of 2.4 (95% CI, 1.4–4.1). These results indicate that a discrete illness or injury is not required to precipitate disability among older persons who are physically frail. For these vulnerable individuals, relatively subtle perturbations in physiologic status or the loss of compensatory strategies may be sufficient to precipitate disability (Campbell & Buchner, 1997; Fried, Herdman, Kuhn, Rubin, & Turano, 1991). Elucidating this common pathway to disability is important because interventions that enhance physical capabilities and augment compensatory strategies, such as prehabilitation (Gill et al., 2003), have been shown to prevent functional decline in physically frail older persons (Gill et al., 2002).

Serious Fall Injuries.—Prompted by our earlier findings (Gill, Allore, et al., 2004b, 2010), we conducted two additional studies that focused specifically on serious fall injuries. In the first (Gill et al., 2013a), we tested the hypotheses that older persons who experienced an injurious fall leading to hospitalization would have worse disability outcomes over a 6-month period and a higher likelihood of a long-term nursing home admission than their counterparts who were hospitalized for a non-fall-related reason, and that these associations would be observed not only for hip fracture but also for other fall-related injuries. We matched 122 hospitalizations for an injurious fall to 241 non-fall-related hospitalizations. Participants were evaluated monthly for disability in 13 activities (four basic, five instrumental, and four mobility) and admission to a nursing home from 1998 to 2010. For both hip fracture and other fall-related injuries, the disability scores were significantly greater during each of the first 6 months after hospitalization than for the non-fall-related admissions, with adjusted risk ratios at 6 months of 1.5 (95% CI, 1.3–1.7) for hip fracture and 1.4 (95% CI, 1.2–1.6) for other fall-related injuries. The likelihood of having a long-term nursing home admission was considerably greater after hospitalization for a hip fracture and other fall-related injury than for a non-fall-related reason, with adjusted odds

ratios of 3.3 (95% CI, 1.3–8.3) and 3.2 (95% CI, 1.3–7.8), respectively. These findings are important because injurious falls are costly and preventable (Centers for Disease Control and Prevention, 2014; Gillespie et al., 2012; Tinetti et al., 2008). Based on evidence that has accumulated over the past two decades, the U.S. Preventive Services Task Force now recommends exercise or physical therapy and vitamin D supplementation to prevent falls in community-living persons aged 65 or older who are at increased risk for falls (Moyer & U.S. Preventive Services Task Force, 2012).

Although a serious fall injury is often a devastating event, little is known about the course of disability (i.e., functional trajectories) prior to a serious fall injury or the relationship between these trajectories and those that follow the fall. In the second study (Gill, Murphy, Gahbauer, & Allore, 2013b), we set out to identify distinct sets of functional trajectories in the year immediately before and after a serious fall injury, to evaluate the relationship between the pre-fall and post-fall trajectories and to determine whether these results differed based on the type of injury. Before the fall, five distinct trajectories were identified: no disability (12.3%), mild disability (26.2%), moderate disability (26.2%), progressive disability (17.7%), and severe disability (17.7%). After the fall, four distinct trajectories were identified: rapid recovery (9.2%), gradual recovery (26.9%), little recovery (20.0%), and no recovery (43.8%). For both hip fractures and other serious fall injuries, the probabilities of the post-fall trajectories were greatly influenced by the pre-fall trajectories, such that rapid recovery was observed only among persons who had no disability or mild disability, and a substantive recovery, defined as rapid or gradual, was highly unlikely among those who had progressive or severe disability. We found that the post-fall trajectories were consistently worse for hip fractures than for the other injuries. These results provide new information about the functional antecedents and consequences of serious fall injuries and underscore the critical importance of the pre-fall functional trajectory on the course of recovery after hip fracture and other serious fall injuries, respectively.

Conclusions

Findings from the PEP Study have demonstrated that the disabling process among many older persons is characterized by multiple and possibly

interrelated disability episodes, even over relatively short periods of time, and that disability often results when an intervening event is superimposed upon a vulnerable host. The high rate of recurrence suggests the need for a paradigm shift on how disability is viewed clinically. In addition to treating acute episodes of disability, ongoing monitoring and maintenance therapies are needed to minimize the frequency and severity of subsequent disability episodes, perhaps guided by the chronic disease model (Von Korff, Gruman, Schaefer, Curry, & Wagner, 1997). Furthermore, given the central role of intervening illnesses and injuries on the disabling process, more aggressive efforts are warranted to prevent their occurrence (Advisory Committee on Immunization Practices, 2013; Straus, Majumdar, & McAlister, 2002; Tinetti et al., 2008; U. S. Preventive Services Task Force, 2009); to manage them more effectively and reduce subsequent complications, especially in the hospital setting (Covinsky et al., 2011; Inouye, 2006; Landefeld, Palmer, Kresevic, Fortinsky, & Kowal, 1995; Rich, 2001); and, after an event, to enhance restorative interventions in the subacute, home care, and outpatient settings (Binder et al., 2004; Hoenig, Nusbaum, & Brummel-Smith, 1997; Tinetti et al., 2002).

Given the frequency of assessments, long duration of follow-up, and recent linkage to Medicare data, the PEP Study will continue to be an outstanding platform for disability research in older persons. In addition, as the number of decedents accrues, the PEP Study will increasingly become a valuable resource for investigating symptoms, function, and health care utilization at the end of life (Chaudhry et al., 2013).

Supplementary Material

Supplementary material can be found at: <http://gerontologist.oxford-journals.org>.

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