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Severity, timing, and structure of disability

Summary

Objectives: Severity and timing are key aspects of disability experience for individuals. They also generate a population's disability structure (prevalence, counts, patterns). We study links among severity, duration, and structure for community-dwelling adults in the US.

Methods: The data source is the National Health Interview Survey Disability Supplement. Disabilities in personal care (ADL), household management (IADL), and physical functions (PLIM) are analyzed.

Results: Many combinations of disabilities are possible, but just a few are frequent; the top-10 patterns cover 70% of ADL, 89% of IADL, and 47% of PLIM disabled adults. Hierarchical patterns are common for ADLs and IADLs. People with many disabilities also have more-severe ones, and their disabilities often started at the same time.

Conclusions: Disability structure reflects severity and timing of specific disabilities, sometimes strongly, and other times weakly due to exit processes from the community. Assumptions that disability occurs in "hard" tasks first and "easy" ones last, and that hard-and-early connotes mild disability whereas easy-and-late connotes severe, need direct empirical testing.

Keywords: **Disability – Severity – Duration – Prevalence – Hierarchy.**

Disability severity and timing are important features of an individual's disability experience. They also generate disability structure, that is prevalence, counts, and patterns of disabilities for the population. We study the traces of severity and duration (time since disability first started) in disability structure for community-dwelling adults in the US. The disabilities relate to personal care (ADL), household management (IADL), and basic physical functions (PLIM). We discuss how longstanding premises about the nexus of severity, timing, and structure can be put to direct empirical test.

Background

We begin with definitions. Disability is the difficulty doing a task on one's own due to health. Severity is the degree of difficulty in accomplishing the task. Duration is how long a disability lasts, based on times of onset and remission. Key features of disability structure are prevalence, counts, and patterns. Prevalence is the rate of disability presence in the population. Count is the number of disabilities that people have, and pattern is the specific combination of them. Some patterns are hierarchical, meaning the component disabilities can be ranked along a single underlying dimension.

The notion of disability hierarchy was launched by Katz and colleagues (Katz & Akpom 1976; Katz et al. 1963; 1970). The research team handcrafted the Index of ADL, a scale indicating independence in "activities of daily living" (a term they coined; includes bathe, dress, toilet, transfer, continence, and feeding). Each activity is scored by whether someone has assistance (personal or special equipment) or not. Combinations of scores are arranged into seven grades (A–G) ranging from complete independence to complete dependence; a residual category contains people with other patterns. Katz and colleagues evaluated the Index of ADL in various samples of older patients. The research yielded these results: First, most (95–96%) people have disability profiles fitting one of the seven grades; the residual group is tiny (4–5%). This is not surprising since the scale has loose premises for inclusion in some grades (B–F). Second, the index is a good predictor of prospective outcomes such as formal home care, mobility, home confinement, and

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institutionalization. Third, the team posited that the scale reflects disability timing, namely, that bathing dependence occurs first, and feeding dependence last. They conducted no studies of disability onsets, but did conduct several of functional recovery (disability remission). These showed that after medical or rehabilitation services, people regain independence in reverse scale order: feeding and continence first, dressing and bathing last (Katz et al. 1963; 1967). Lastly, the team made a strong assertion about disability dynamics, stating that adult acquisition of disabilities takes the opposite course of childhood development of abilities. The first ADL ability that children acquire is the last ADL ability that adults lose. The assertion was not tested empirically but gathered strength over time by repetition.

In ensuing decades, disability hierarchy has been studied with many variations in types of people (community dwellers, patients, nursing home residents), domains of disability (ADL, IADL, mobility, social activities), aspects of disability (dependency, difficulty, tiredness, slowness), and scaling techniques. Most studies concentrate on middle-aged and older persons. We review briefly analytic techniques, main substantive results, and underlying premises.

Disability scales can be statistically derived, or they can be handcrafted. Derived scales have two forms: Guttman scaling is deterministic, so people are included if they have exactly one of the ranked patterns (McIver & Carmines 1981). Newer scaling techniques (identified as Rasch, Mokken, item response theory, and latent class scaling analysis) are probabilistic with less strict criteria for how observed data fit the derived scale (Andrich 1988; Niemoller & Von Schuur 1983; van der Linden & Hambleton 1997). For handcrafted scales, analysts rank the disability domains according to what they think is more severe and less severe. A typical ordering is institutional residence, ADL disability, IADL disability, and PLIM disability. People are scored into their "worst" domain (Branch & Ku 1989; Manton et al. 1993; Mor et al. 1994).

Central empirical results are as follows: First, the Index of ADL scales well (Brorsson & Asberg 1984; Lazaridis et al. 1994; Siu et al. 1990; Travis & McAuley 1990). It is not preferred by contemporary researchers due to the vagueness of some grades (noted above). Second, researchers typically choose a set of disability items with good conceptual coverage of one or several domains, then submit the set to scaling procedures. Virtually all generate good scales. Sometimes scale dimensions closely replicate item domains, and other times, they redistribute items in new ways, prompting reconceptualization. We cite several reports (Asberg & Sonn 1988; Avlund et al. 1993; Ferrucci et al. 1998; Kempen et al. 1995; Lazaridis et al. 1994; Norstrom & Thorslund 1991; Spector & Fleishman 1998); a fuller list is available on request. Third, scales for a given domain agree on which activities are the endpoints, but vary in their ordering of middle-ranked activities (e.g., Heinemann et al. 1993; Katz et al. 1963; Kempen & Suurmeijer 1990; Travis & McAuley 1990).

Hierarchy research contains premises about severity and timing of disabilities. First, severity is assumed to be the underlying dimension for disability scales. It is crucial to note here that severity has two meanings in disability research. In standard hierarchy research, it refers to the intrinsic nature of tasks; disability in "hard" tasks is assumed mild, and in "easy" tasks, severe. Elsewhere in disability research, severity refers to the degree of difficulty doing a given task. Recent hierarchy research includes the within-task usage, as well as the across-task one. Second, hierarchy is assumed to come about in a cumulative way, with the least severe disabilities first, and the most severe ones last. Summing up, the severity and timing assumptions are sometimes explicit (e.g., Avlund et al. 1993; Bebbington 1977; Daltroy et al. 1992; Ferrucci et al. 1998; Linacre et al. 1994; Morris et al. 1999; Rosow & Breslau 1966), and other times implicit. We will consider the premises more fully in the Discussion.

Methods

Data source

We use the National Health Interview Survey Disability Supplement (NHIS-D), a survey conducted in 1994 and 1995 by the National Center for Health Statistics (NCHS) to study disability in the US community-dwelling population of all ages. NHIS-D accompanied the National Health Interview Survey (NHIS), a continuous survey of health of the US civilian noninstitutional population. NHIS-D had two parts: Phase One obtained disability information for all household members. It generated national estimates of disability and also served as a screener to identify disabled respondents. Phase Two (Disability Follow-up Survey) was conducted some time after Phase One. It asked persons with disabilities about details of disability experience and services. NHIS-D questionnaires and data are publicly available (Adams & Marano 1995; www.cdc.gov/nchs).

This analysis uses 1994 Phase One data for adults (ages 18+). We analyze disability severity, duration, and structure in each domain (ADL, IADL, PLIM) and compare results across domains. The analyses are innovative, so we look at the whole adult population, not age-sex subgroups. Some results for all adults may vary by gender or age, but we leave that for others to study. Disability prevalence rates for age-sex

groups can be obtained from NCHS (www.cdc.gov/nchs) or the Disability Statistics Center (dsc.ucsf.edu [sic]).

Variables

(1) ADLs. Difficulty in six personal care activities due to health was queried in NHIS-D Phase One. The activities, with their exact questionnaire wording and order, are: bathing or showering; dressing; eating; getting in and out of bed or chairs; using the toilet including getting to the toilet; getting around inside the home. A person is scored as having disability in a given ADL if for health reasons, s/he (a) uses assistance for the task or (b) does not use assistance but has difficulty doing the task or doesn't do it. Assistance is personal help, reminder or supervision, or special equipment.

(2) IADLs. Difficulty in six household management activities due to health was queried: preparing their own meals; shopping for personal items, such as toilet items or medicine; managing money, such as keeping track of expenses or paying bills; using the telephone; doing heavy housework around the house like scrubbing floors, washing windows, and doing heavy yard work; doing light housework around the house like doing dishes, straightening up, light cleaning, or taking out the trash. The operational rule for scoring IADL disability is same as above. For IADLs, assistance is personal help or supervision.

(3) PLIMs. Difficulty in eight physical tasks was queried: lifting something as heavy as 10 pounds, such as a full bag of groceries; walking up 10 steps without resting; walking a quarter of a mile, about 3 city blocks; standing for about 20 minutes; bending down from a standing position to pick up an object from the floor, for example, a shoe; reaching up over the head or reaching out as if to shake someone's hand; using fingers to grasp or handle something, such as picking up a glass from a table; holding a pen or pencil. A person is scored as having disability in a given PLIM if s/he says Yes. Health-relatedness is assumed. Conceptually, PLIMs are functional limitations that affect risks of ADL/IADL disabilities (Pope & Tarlov 1991; Verbrugge & Jette 1994). Solely for economy, we call PLIMs disability herein. For the ADL/IADL/PLIM items, the few cases with missing data ("don't know", not ascertained) are coded to the mode "no disability".

Severity is degree of difficulty doing a task on one's own. For people with disability, response categories are some, a lot, and unable ("completely unable" for PLIMs), scored 1–3. Unassisted people rated their actual degree of difficulty, and assisted people gave a hypothetical answer. Cases with missing data are assigned the mode of their (un)assisted subgroup.

Duration is years since first onset of a disability. The survey asked age at first onset for each disability; duration equals current age minus age at first onset. People whose disability began at current age are scored 0.5 year. For those stating an age range, we applied a detailed imputation procedure that assigned the mean observed onset age of same age-sex-race persons with the disability (Verbrugge & Sevak 2002). Percents imputed were 12–19% for the specific ADL disabilities, 14–22% for IADLs, and 5–6% for PLIMs. The duration variable can overestimate time spent disabled because any remission periods are not taken into account (they were not queried in NHIS-D). Still, it is a good sociological indicator of experience and concern for a disability since even if remissions occur, anxiety and caution are likely to persist. NHIS-D has no information on prior disabilities not current at interview time.

We constructed variables for counts and patterns. (1) Counts are the number of tasks with disability in each domain. The analyses are for disabled-in-domain persons, so ranges are 1–6 for the ADL and IADL domains, and 1–8 for PLIM. (2) Patterns are combinations of specific disabilities. To create these, we arranged disabilities by prevalence, with highest prevalence first. The order for ADLs is Bathe – Dress – Transfer – Inside – Toilet – Eat. Each person is coded with an array of 0's and 1's. For example, the pattern 110000 is for people with just Bathe and Dress disabilities. The IADL prevalence order is Heavy Housework – Shop – Light Housework – Meals – Money – Phone. The PLIM order is Walk – Bend – Stand – Steps – Lift – Reach – Grasp – Hold. Excluding the all-0's pattern (no disability in domain), there are 63 possible patterns for ADLs, 63 for IADLs, and 255 for PLIMs. (3) Perfect hierarchy is a family of patterns with scaled structure. We use prevalence as the ranking dimension; this is because statistically-derived scales in the literature closely follow prevalence. A strict Guttman definition is applied for choosing hierarchical patterns, namely, for any given disability in a pattern, all disabilities with higher prevalence are also present. For ADLs and IADLs, the perfect hierarchy families have six patterns: 100000, 110000, 111000, 111100, 111110, 111111. For PLIMs, it has eight patterns: 10000000, ..., 11111111.

Samples and weights

NHIS-D has a multistage, cluster probability sample of households. NCHS provides weights that adjust for sample design and nonresponse so results are representative of the US civilian noninstitutional population. The weights generate national estimates of numbers of persons, which can be hundreds of thousands or millions. For ease of analysis, we rescaled the weights back to the original sample size. Our

Table 1 Prevalence and counts of ADL, IADL, and PLIM disabilities

Prevalence				Count	
	All adults	Disabled in domain	N		Disabled in domain[a]
ADL					
Bathe	2.0%	73.7%	1 642	1	37.6%
Dress	1.3	48.1	1 079	2	20.3
Transfer	1.3	47.5	1 066	3	12.5
Inside	1.2	42.8	947	4	9.1
Toilet	1.0	35.8	792	5	11.1
Eat	0.4	16.0	356	6	9.4
Any ADL disability	2.8%		2 215	Mean	2.64
IADL					
Heavy Housework	7.2%	92.6%	5 824	1	56.6%
Shop	2.7	34.8	2 229	2	15.6
Light Housework	2.2	28.8	1 810	3	8.5
Meals	1.7	21.7	1 379	4	8.5
Money	1.5	19.7	1 233	5	5.3
Phone	0.7	9.2	580	6	5.5
Any IADL disability	7.8%		6 279	Mean	2.07
PLIM					
Walk	7.6%	57.6%	6 176	1	34.9%
Bend	6.3	48.1	5 099	2	19.1
Stand	5.9	44.8	4 822	3	13.0
Steps	5.7	43.5	4 710	4	11.4
Lift	5.3	40.2	4 342	5	10.3
Reach	2.7	20.6	2 195	6	5.1
Grasp	2.4	18.7	1 982	7	3.2
Hold	1.7	12.8	1 363	8	3.0
Any PLIM disability	13.1%		10 630	Mean	2.14

Data source: National Health Interview Survey Disability Supplement, Phase One, 1994. Results are weighted to be representative of the civilian non-institutional population ages 18+. N's are raw sample sizes. The three domains are personal care tasks (ADL), household management tasks (ADL), and basic physical functions (PLIM)

[a] Percents sum to 100.0% in each domain

analyses do not involve tests of difference or confidence intervals for point estimates, so complex variance estimation was not applied. NHIS-D 1994 Phase One has a sample of 77437 adults. Raw counts for disability domains are 2215 ADL, 6279 IADL, and 10630 PLIM. Weighted rescaled counts are 2132.2 ADL, 6003.0 IADL, and 10161.4 PLIM.

Hypotheses

Our hypotheses derive from the literature on disability hierarchy, and are shaped to suit the cross-sectional nature of the data set. Here, severity is within-task severity, and timing is duration since onset. (1) High-prevalence disabilities have low severity but long duration; conversely, low-prevalence disabilities have high severity but short duration. For duration, the rationale is that people readily incur limitations in complex tasks like bathing, heavy housework, and distance walking during life, whereas limitations in simple tasks like eating, using the phone, and holding objects occur only if someone is very frail or extremely ill, which is usually late in life. Thus, high-prevalence disabilities tend to arrive earliest. For severity, the rationale is that disability in complex tasks is typically partial (less severe), and more complete (more severe) for simple ones; this is tentative and we shall see what the data yield. (2) High numbers of disabilities are associated with high severity and long duration. The rationales are that disabilities gradually worsen and also cumulate over life.

Results

Disability structure

Prevalences of ADL, IADL, and PLIM disabilities for US community-dwelling adults are in Table 1. The disabilities in each domain are arranged from highest to lowest prevalence. Overall, adults are most likely to have PLIM disability (13.1%), with IADL disability next (7.8%), and ADL disability least likely (2.8%). For the specific disabilities, prevalences range 7.6% (Walk) to 1.7% (Hold) for PLIMs; 7.2% (Heavy Housework) to 0.7% (Phone) for IADLs; and 2.0% (Bathe) to 0.4% (Eat) for ADLs. Ranges for the three domains overlap; for example, despite typically higher

prevalence for PLIM/IADLs than ADLs, one PLIM (Hold) and three IADLs (Meals, Money, Phone) have lower prevalences than the top ADL (Bathe). For persons with disability in a domain, the specific disabilities show higher prevalences and maintain the same ranks. For example, 73.7% of the ADL-disabled persons have Bathe difficulty, 92.6% of IADL-disabled persons have Heavy Housework difficulty, and 57.6% of PLIM-disabled persons have Walk difficulty.

For counts, people with disability in a given domain usually have just one or two disabilities (Table 1). ADL-disabled persons have more in-domain disabilities than the other two groups. This means ADLs have higher multiplicity than IADLs and PLIMs.

Most possible patterns of ADLs, IADLs, and PLIMs do occur in real life, but only a few patterns are frequent. In the NHIS-D sample, 55 of 63 (87%) of ADL patterns exist, 50 of 63 (79%) of IADL patterns, and 230 of 255 (94%) PLIM patterns. Still, the top-ten patterns cover the great majority of persons in a domain: 70.2% for ADLs, and 89.0% for IADLs (Table 2). For IADLs, a key reason for the high percentage is the Heavy Housework Only pattern (52.0%). Dropping Heavy Housework entirely from the roster of IADLs, there are 31 possible patterns; the top-ten cover 86.4% of IADL-disabled persons – still the great majority. For PLIMs, the top-ten patterns cover just 47.2% of PLIM-disabled persons; the top-30 cover 76.5%.

Disabilities are not independent; they co-occur more than expected by chance. For each leading pattern, we calculated the expected percent having a pattern assuming independence of disabilities, then took the ratio of observed to expected percents. For the top-ten patterns, ratios exceed 1.0 for 7 ADL, 6 IADL, and all PLIM patterns (Table 2). Full patterns (all 1's) greatly exceed chance expectation. Non-independence is a signal that disabilities in the pattern have shared causal factors. Severe injury, acute illness, or sharp health decline can cause several or many disabilities to start all at once. We report below that simultaneous onsets are especially apparent in full patterns.

Leading patterns tend to be simple, involving one or two disabilities. This is true for 7 of 10 ADL, 5 IADL, and 6 PLIM leading patterns. These low-count patterns usually involve high-prevalence disabilities, but some of the 1-disability patterns are mid-prevalence disabilities (Inside Only for ADLs, Money Only for IADLs, Lift Only and Steps Only for PLIMs). Despite the tendency to simplicity, full patterns are always among the leading ones. They hold rank 3 for ADLs (9.4% of ADL-disabled people have difficulty in all the tasks), rank 5 for IADLs (5.5%), and rank 8 for PLIMs (3.0%).

Prevalence, count, and pattern entwine with each other. We showed above that leading disability patterns tend to be low-count, involving high or middle prevalence disabilities. By other analyses, we also found that disability prevalence and count have an inverse tie; the most prevalent disabilities are often solo, whereas the least prevalent ones occur in high counts. For ADLs, Bathe is most often in the 1-disability count, mid-prevalence disabilities in 2–5 counts, and Eat in 6-disability counts. For IADLs, Heavy Housework is most often in a 1-disability count and least often in 5- and 6-counts, mid-prevalence disabilities concentrate in 2–5 counts, and Phone is most prominent in 6-disability counts.

Table 2 Frequent patterns of ADL, IADL, and PLIM disabilities (among persons with disability in the domain)

ADL Rank	Pattern (Bathe – Dress – Transfer – Inside – Toilet – Eat)	Percent	Ratio[a]
1	100000 Bathe Only	18.9%	3.0
2	111110 All ADLs except Eat	9.9	4.6
3	111111 All ADLs	9.4	22.9
4	110000 Bathe, Dress	8.5	1.5
5	001000 Transfer Only	7.3	3.6
6	000100 Inside Only	5.3	3.2
7	010000 Dress Only	3.3	1.6
8	111000 Bathe, Dress, Transfer	2.8	0.6
9	100100 Bathe, Inside	2.4	0.5
10	101000 Bathe, Transfer	2.4	0.4
IADL Rank	**Pattern (Heavy Housework – Shop – Light Housework – Meals – Money – Phone)**	**Percent**	**Ratio**
1	100000 Heavy Housework Only	52.0%	2.1
2	101000 Heavy & Light Housework	6.6	0.7
3	111100 All IADLs except Money, Phone	5.9	4.0
4	110000 Heavy Housework, Shop	5.8	0.4
5	111111 All IADLs	5.5	>100
6	111110 All IADLs except Phone	4.0	11.1
7	111000 Heavy & Light Housework, Shop	3.8	0.7
8	000010 Money Only	2.3	4.7
9	110010 Heavy & Light Housework, Money	1.6	0.5
10	010000 Shop Only	1.5	1.4
PLIM Rank	**Pattern (Walk – Bend – Stand – Steps – Lift – Reach – Grasp – Hold)**	**Percent**	**Ratio**
1	10000000 Walk Only	8.8%	2.8
2	01000000 Bend Only	7.7	3.6
3	11111000 Walk, Bend, Stand, Steps, Lift	5.5	4.5
4	00001000 Lift Only	5.1	3.3
5	00100000 Stand Only	4.8	2.5
6	10010000 Walk, Steps	3.7	1.5
7	11110000 Walk, Bend, Stand, Steps	3.1	1.7
8	11111111 All PLIMs	3.0	>250
9	00010000 Steps Only	2.9	1.6
10	11111100 All PLIMS except Grasp, Hold	2.6	8.2

Data source: National Health Interview Survey Disability Supplement, Phase One, 1994. Results are weighted to be representative of the civilian noninstitutional population ages 18+

[a] Ratio of observed prevalence to expected (assumes independence) prevalence. For a given pattern, the expected value is obtained by multiplying the probabilities of 1's and 0's. For example, for 110000 (Bathe, Dress), the expected probability is 0.737 x 0.481 x 0.525 x 0.572 x 0.642 x 0.840 = 0.057, or 5.7%. The ratio of observed 8.5% to expected 5.7% = 1.5. Observed prevalences are in Table 1

Table 3 Perfect hierarchy of ADL, IADL, and PLIM disabilities (among persons with disability in the domain) (percents)

ADL		IADL		PLIM	
100000	18.9 %	100000	52.0 %	10000000	8.8 %
110000	8.5	110000	5.8[a]	11000000	1.7[a, b]
111000	2.8[a]	111000	3.8[a]	11100000	1.3[a, b]
111100	2.3[a, b]	111100	5.9	11110000	3.1
111110	9.9	111110	4.0	11111000	5.5
111111	9.4	111111	5.5	11111100	2.6
				11111110	0.9[b]
				11111111	3.0
Total	51.8 %		77.0 %		26.9 %
Ratio[c]	2.2		1.7		2.3

Data source: National Health Interview Survey Disability Supplement, Phase One, 1994. Results are weighted to be representative of the civilian noninstitutional population ages 18+

[a] These patterns have ratios of observed to expected prevalence ≤1.0; all others have ratios >1.0

[b] These patterns not in the top-ten for the domain; all others are lead ing patterns

[c] See Table 2, footnote a for calculation procedure for ratio of observed to expected prevalence

For PLIMs, the relationship weakens but is still evident. Charts for these results are available on request.

Perfect hierarchy

Perfect hierarchy is common for ADL-disabled persons (51.8 %) and IADL-disabled persons (77.0 %) (Tab. 3). Heavy Housework Only undergirds the IADL results; dropping Heavy Housework from the IADL roster and using five activities, hierarchy occurs for 55.6 % of IADL-disabled persons. For PLIMs, perfect hierarchy is uncommon (26.9 %). In all of the domains, perfect hierarchy occurs twice as often as chance expectation, even for PLIMs. Ratios of observed to expected percents are 2.2 for ADLs, 1.7 IADLs (1.5 excluding Heavy Housework), and 2.3 PLIMs. Most of the specific hierarchical patterns also have ratios above 1.0. This is true for 4 ADL, 4 IADL, and 6 PLIM hierarchy patterns (exceptions noted by[a]). We also note that perfect hierarchy patterns are usually among the top-ten for a domain. This applies for 5 ADL, all 6 IADL, and 5 PLIM hierarchical patterns (exceptions noted by[b]).

Table 4 Severity and duration by disability prevalence and count[a] (among persons with the specific disability)

By Prevalence[b]			By Count		
	Average severity	Average duration		Average severity[c]	Average duration[c]
ADL			ADL		
Bathe	2.14	7.52	1	1.71	7.87
Dress	1.76	7.76	2	1.67	7.26
Transfer	1.70	7.20	3	1.82	7.27
Inside	2.15	6.65	4	1.81	7.22
Toilet	2.16	6.78	5	2.21	6.52
Eat	1.71	7.53	6	2.32	7.63
IADL			IADL		
Heavy Housework	2.57	7.52	1	2.39	7.77
Shop	2.56	8.47	2	2.40	7.78
Light Housework	2.37	6.94	3	2.39	8.20
Meals	2.38	8.52	4	2.51	8.00
Money	2.45	12.13	5	2.67	8.72
Phone	2.42	14.14	6	2.76	10.63
PLIM			PLIM		
Walk	1.95	7.06	1	1.33	7.75
Bend	1.70	7.79	2	1.46	7.17
Stand	1.80	7.77	3	1.60	6.96
Steps	1.78	7.31	4	1.82	7.74
Lift	1.93	7.52	5	1.97	7.09
Reach	1.68	7.26	6	2.01	7.20
Grasp	1.42	7.69	7	2.02	8.59
Hold	1.30	7.55	8	2.28	8.03

Data Source: National Health Interview Survey Disability Supplement, Phase One, 1994. Results are weighted to be representative of the civilian noninstitutional population ages 18+

[a] Severity scores range from 1 (low severity) to 3 (high). Duration is years since first onset

[b] Disabilities are ordered from highest to lowest prevalence in each domain

[c] For each person, the mean severity (or duration) of his/her disabilities was computed; averages of those values are shown here

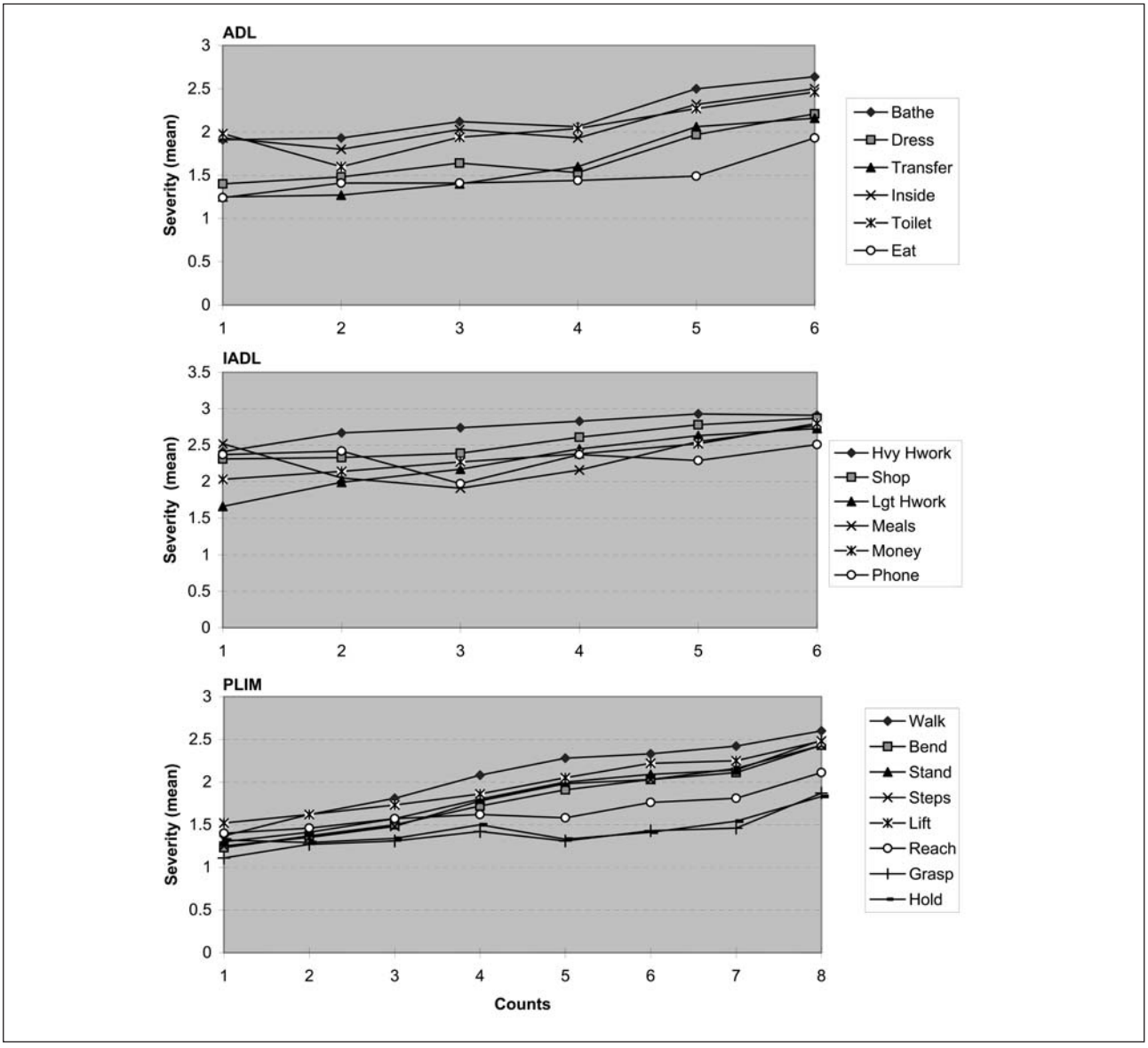

Figure 1 Severity of each disability, by count, in ADL/IADL/PLIM domains

Severity and duration

We hypothesized that severity decreases, and duration increases, with disability prevalence. The results are contrary. Disability severity has little link to prevalence (Tab. 4). Average severity does not decline as prevalence rises. The only systematic result is opposite: *Top-prevalence disabilities (Bathe, Heavy Housework, Walk) have highest or nearly so severity.* And, duration does not increase with prevalence. The only systematic result is opposite: *Lowest-prevalence ADL and IADL disabilities (Eat, Money, Phone) have longest or nearly so duration.*

We hypothesized that severity and duration rise with disability number. The results largely concur. First, *severity rises with number of disabilities* (Tab. 4). The table shows overall severity (based on mean severity of each person's n disabilities, without attention to which disabilities they are). Looking instead at each specific disability, we also find that severity rises as it enters higher counts (Fig. 1). We found that these results hold among people with hierarchical patterns: Overall severity rises with count; and further, as each disability is drawn into higher counts, its severity rises (figures on request). Second, *duration increases with number of IADLs but not ADL/PLIMs. Still, in all domains, people with the top count have longest or nearly so durations.* Looking at each specific disability, no general relationship of duration with count is perceptible (Fig. 2). One consistent and

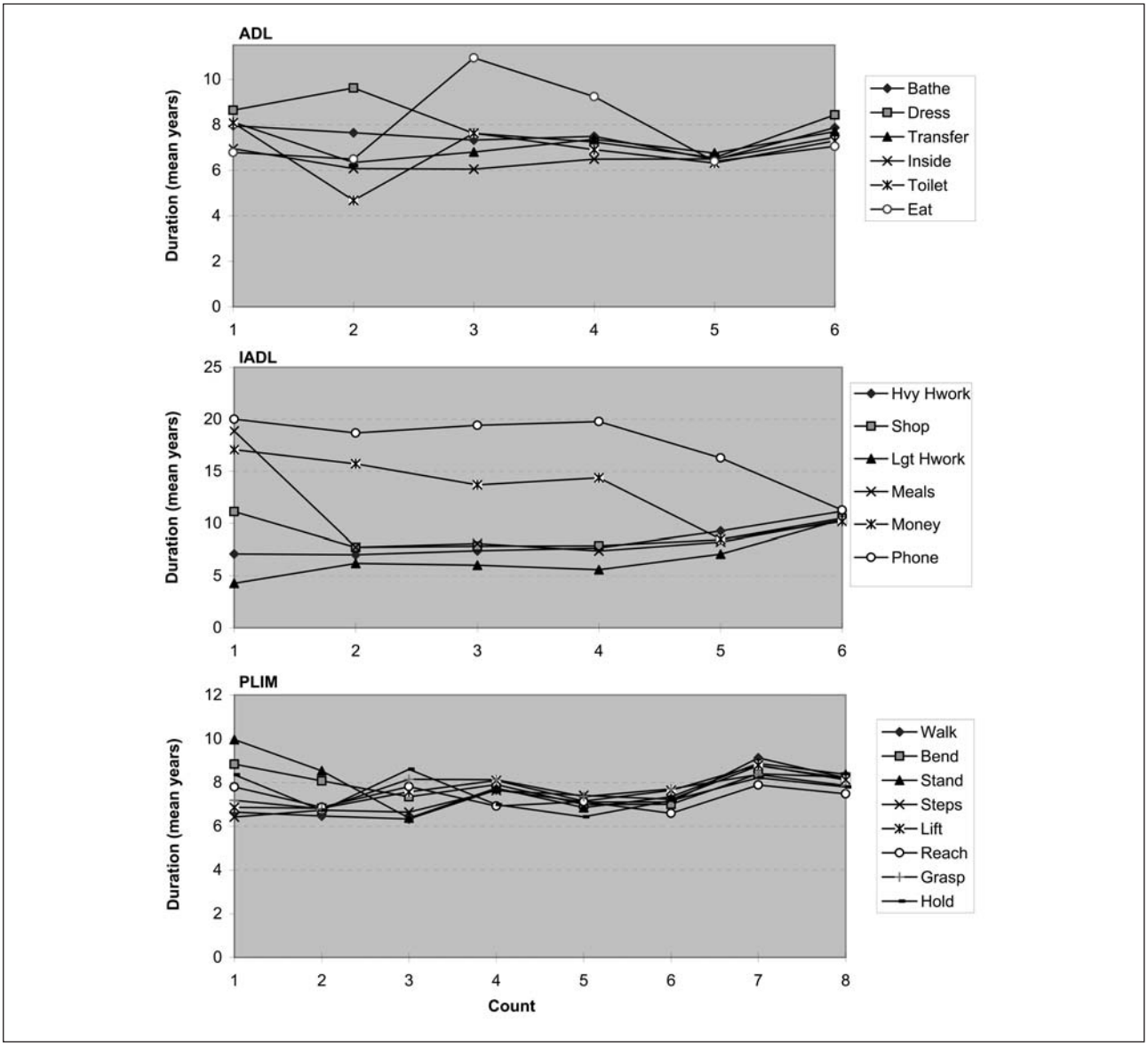

Figure 2 Duration of each disability, by count, in ADL/IADL/PLIM domains

important result does appear: Durations of disabilities tend to converge at high counts. This means that people with many disabilities often acquired them all at the same time. These results hold in the perfect hierarchy family: High counts have long(est) duration, for overall mean years and each disability's duration. Here, IADLs show signs of positive linear association. For this family, simultaneous or nearly-so onset times occur at all counts, not just high ones (figures on request).

Summary of results

The main empirical results are as follows:

(1) ADL-disabled people have more in-domain disabilities than do IADL- and PLIM-disabled people. This multiplicity means that community-dwellers with ADLs have especially difficult daily lives. (2) Only a small number of patterns are frequent, and they cover the majority of persons in each domain. Leading patterns usually have just one or two disabilities, but do include the full patterns too. (3) Perfect hierarchy is common for ADL and IADL disabilities. It occurs twice as often as expected in all domains, even PLIMs. (4) Hypotheses about how severity and duration are linked to prevalence are not supported. Two contrary results occur: High-prevalence disabilities have high severity, and low-prevalence ones have long durations. (5) But hypotheses about how severity and duration are linked to count are

largely supported. Severity rises with number of disabilities. Duration has weaker results, but highest counts do tend to have long(est) durations.

Discussion

The hypotheses posited links of disability severity and duration to disability structure. The results show moderate to weak links. To explain this, we present a potential scenario that would generate tight links among the three aspects, then we discuss how real life dynamics cause some unhinging of the links.

The scenario takes a large birth cohort that ages without institutionalization or death. As people grow older, many encounter disability in their activities. Chances of disability are higher for tasks with high demands, namely, those requiring many or high level skills. Disability in such tasks is usually partial; just one or several relevant skills are compromised, rather than all of them. Once a disability starts, it persists. At some great age, say 110, everyone departs to institutions or death. Formally stated, this scenario presumes a fixed population and an absorbing disability process. Disabilities cumulate for individuals and the population, and tight conjunctions of prevalence, count, hierarchy, severity, and duration invariably emerge. High prevalence, low severity, and long duration join together, and so do low prevalence, high severity, and short duration. As numbers of disabilities rise for individuals, overall severity and duration rise. Hierarchy is assured.

Real life has more dynamics than the scenario. It includes strong "exit" processes as people age, namely, disability remission, institutionalization, and death. In formal terms, real populations experience attrition, and disability is non-absorbing. At any given time, the disability structure of the community-dwelling population is a residue of entry (disability acquisition) and exit (remission, institutionalization, death) processes. Exits weaken the connections among disability severity, duration, and structure. (We ignore immigration/emigration, whose role is relatively minor.)

Our analyses show that some linkages do remain strong in real life, while others erode. (1) The strongest tie is for severity and count. As a person's number of disabilities rises, so does severity of their disabilities. (2) Duration and count are consistently linked in one respect: People with many disabilities have long(est) durations. We have shown elsewhere that people often acquire all their disabilities at the same time, whether few or many (Verbrugge & Sevak 2002). Simultaneous onsets greatly dissipate traces of timing in structure. (3) Severity and duration are not linked with prevalence except for two unusual results: high(est) severity for the most prevalent disabilities, and long(est) duration for the least prevalent ones. These are actually clues that exit processes are at work. People who have difficulty in simple tasks such as eating, using a phone, or holding objects are in a serious situation, and they readily exit to death or institutions. Exit is especially swift if someone is unable to do the task at all without help, that is, severe disability. People with such disabilities who do remain in the community are quite special, with milder dysfunctions and ultimately long durations because accommodations have been found. For mid- and high-prevalence disabilities, exit processes operate less vigorously. Altogether, real-world exits leave the unusual structural residues we noted in for community dwellers. (4) PLIMs have weaker results overall than ADLs and IADLs: Leading PLIM patterns cover half as many persons, the full pattern has lower prevalence and ranks lower among the top-ten, and perfect hierarchy is half as common. The weaker results occur because PLIM items include two kinds of tasks, some emphasizing upper extremity, and others, lower extremity actions. Dysfunctions in the two zones often arise from very different health problems. Disability scales routinely show that upper-extremity tasks, especially fine motor ones, rank lower than do lower-extremity tasks in a scale, and the items may generate separate scales altogether (van Boxel et al. 1995). (5) People with perfect hierarchy produce especially clear results. The family is well-defined and less heterogeneous than all disabled-in-domain persons. That gives better chances of seeing underlying systematic results.

The scenario described above is a hierarchical one. We stated it in terms of within-task severity and duration since first onset, in order to compare with the NHIS-D empirical results. Now we state the scenario in classic manner, positing links among task difficulty, across-task severity, and disability timing. The core premises are as follows: Disability occurs in hard tasks first and easy tasks last. "Hard and early" signifies mild disability, whereas "easy and late" signifies severe disability.

The argument for this nexus of task type, severity, and timing is rarely spelled out, so we will state it clearly: Every task involves component subtasks (complexity), level of activity (load), and time features (speed, frequency, duration). (1) A "hard" task has high demand for human abilities. It requires many, or high level, or high time-related skills. When health problems impair any of the necessary skills, difficulty doing the task readily ensues. Most requisite skills are not compromised, and people find ways to continue doing a task with some degree of difficulty. Moreover, the disability typically has few implications for social participation, assistance, and survival. For these two reasons, disability in high-de-

mand tasks is overall deemed "mild". Because "hard" tasks involve so many abilities, disabilities in them tend to be the earliest ones in a person's life. (2) By contrast, an "easy" task has low demand. It requires few, or low level, or low time-related skills. Impairment in a required skill can inhibit doing the task at all, and assistance is often needed to accomplish it. Moreover, if the task is necessary for survival, there is high risk of mortality from the disability. For these two reasons, disability in low-demand tasks is considered "severe". Only the most frail or ill persons have difficulty doing "easy" tasks, so these disabilities tend to be the last in people's lives. Is this argument right? Is this how things happen in real life? Pertinent empirical data are scant, and we will suggest what such data would be like.

Severity premise

We do not have empirical evidence on how tasks differ in demand. Formal task analysis of ADLs, IADLs, and PLIMs is needed to identify and score their demand features, then develop an overall score of task demand for each activity. The enterprise is complicated by cultural differences in typical procedures and social standards for ADL and IADL tasks, within and across populations. Once it is accomplished, we can ascertain if disabilities in high-demand tasks are usually partial (limitations in some subtasks, but not others), while disabilities in low-demand tasks are more complete (limitations in all or almost all subtasks). Task scores can be compared with how the tasks rank on disability scales. Most importantly, task demand scores for ADL/IADL/PLIM disabilities can be tested for predictive ability of prospective outcomes (e.g., unemployment, social isolation, home care, institutionalization, death).

How task demand relates to respondent reports of difficulty should also be studied. Conceptually, the two kinds of severity are distinct; people can have severe trouble in an easy task, or mild trouble in a hard one. Empirical links between them may be faint in the community-dwelling population, in part because persons with severe degree-of-difficulty tend to exit. Within-task severity has been integrated into some recent statistically-derived disability scales, and they successfully rank both tasks and task-specific degrees of difficulty (Heinemann et al. 1993; Kempen et al. 1995; 1996; Kempen & Suurmeijer 1990; Linacre et al. 1994; van Boxel et al. 1995; van Buuren & Hopman-Rock 2001). The predictive ability of across-task and within-task severity should be compared; it is likely that both are needed for good prediction.

Timing premise

The overarching question is whether disabilities tend to enter people's lives in a particular sequence, and remit in another one. Do disabilities in hard tasks typically come earliest, and disabilities in easy tasks last? Does acquisition typically follow a hierarchical path, and does functional recovery take the opposite one? Is adult disablement the reverse image of childhood ability acquisition?

We first review the small existing evidence on sequences of disability acquisition and recovery. With longitudinal data, Dunlop et al. (1997) show that disability acquisition follows a hierarchical trajectory: walk (first), bathe, bed/chair transfer, dress, toilet, feed (last). Generally stated, tasks requiring substantial lower-extremity abilities incur disability before those requiring mainly upper-extremity ones. Disability remission rates are much lower than acquisition rates (Branch & Ku 1989; Crimmins & Saito 1993; Manton et al. 1993; Mor et al. 1994), and they are based on disability counts or domains rather than specific disabilities. To see remission trajectories of specific disabilities requires data with many years of observation and very large sample sizes. Studies of special populations, especially patients receiving rehabilitation, can offer good evidence about remission. For such groups, some studies report recovery of functional domains, but not of specific disabilities (Fortinsky et al. 1999; Jette et al. 1987; Verbrugge et al. 1994). Remarkably, to date, we have only Katz' own results for specific disabilities (Katz et al. 1963; 1967).

To answer the questions we stated requires longitudinal data of disability trajectories for individuals. With such data, disability onset and remission sequences can be compared with task rankings (and also with statistically derived disability scales). Whether acquisition sequences are opposite to remission sequences can be determined. It may be that remissions follow hierarchy far more strongly than acquisitions do, since remissions tend to be step-by-step, whereas acquisitions are often simultaneous. Lastly, the hypothesis that adult disability onsets take the reverse course of child development of ADL skills is untested. To answer it requires ample empirical understanding of both adults and children.

In conclusion, in the early work on disability hierarchy, Katz and colleagues perceived the importance of disability severity and timing. The Index of ADL was crafted to reflect grades of task severity, and the group perceived the idea of task demand, saying that the activities are arrayed by "the amount of organized activity required by each function" (Katz et al. 1963: 917). Bold and intriguing statements about disability timing were made. Subsequent research on disability hierarchy did not directly study the nexus of task difficulty, disability severity, and disability timing. Technically derived disability scales gave apparent support so the premises became accepted.

It is time to bring the nexus of severity, timing, and structure back to testable hypotheses and empirical research. We have

suggested some routes for that work, but imagination and talent will open others as well.

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Zusammenfassung

Ausmass, Zeitpunkt und Struktur von Behinderung

Fragestellung: Das Ausmass und der Zeitpunkt einer Behinderung sind wesentliche Aspekte im individuellen Erleben der Behinderung. Sie erzeugen auch eine Behinderungsstruktur der Bevölkerung (Prävalenz, Zahlen, Muster). Wir untersuchen Zusammenhänge zwischen Ausmass, Dauer und Struktur für Erwachsene in öffentlichen Einrichtung in den USA.

Methoden: Datenquelle ist das Behindertensupplement der nationalen Gesundheitsbefragung (National Health Interview Survey). Behinderungen in der Körperpflege (ADL), in der Haushaltsführung (IADL) und in körperlichen Funktionen (PLIM) wurden untersucht.

Ergebnisse: Viele Kombinationen von Behinderungen sind denkbar, aber nur wenige sind wirklich häufig. Die 10 häufigsten Muster umfassen zu 70 % ADL-, 89 % IADL- und zu 47 % PLIM-behinderte Erwachsene. Hierarchische Muster sind häufig für ADL- und IADL-Behinderungen. Personen mit Mehrfachbehinderungen haben häufiger schwere Behinderungen, welche oftmals gleichzeitig eintraten.

Schlussfolgerungen: Eine Behinderungsstruktur reflektiert das Ausmass und den Zeitpunkt spezifischer Behinderungen manchmal sehr deutlich und manchmal weniger deutlich, bedingt durch den Wegzug/Austritt aus der Gemeinschaft. Vermutungen, dass Behinderungen in schweren Fällen früher und in leichten Fällen zuletzt auftreten und dass schweres Ausmass und frühes Auftreten eine geringfügige Behinderung bedeuten, während leichtes Ausmass und spätes Auftreten eine schwere Behinderung bedeuten, bedarf einer direkten empirischen Überprüfung.

Résumé

Gravité, temporalité et structure de l'invalidité

Objectifs: La sévérité et temporalité sont des aspects cruciaux de l'invalidité pour les individus. Ils sont générateurs d'une structure d'invalidité au niveau populationnel (prévalence, nombres, profils). Nous étudions les liens entre sévérité, durée et structure parmi des adultes résidant dans des communautés aux Etats-Unis.

Méthodes: La donnée provient du National Health Interview Survey Disability Supplement. L'incapacité sur le plan des activités personnelles, des activités ménagères et des fonctions physiques sont analysées

Résultats: Plusieurs combinaisons d'incapacité sont possibles, mais seules certaines sont fréquentes: les 10 profils principaux couvrent 70 % des incapacités de soins personnels, 89 % des incapacités pour les tâches ménagères et 47 % des incapacités physiques. Des profils hiérarchisés sont fréquents pour les incapacités de soins personnels et de tâches ménagères. Les personnes cumulant les incapacités souffrent également des formes les plus sévères, et leurs incapacités commencent souvent simultanément.

Conclusions: La structure d'incapacité reflète la sévérité et la temporalité des incapacités spécifiques, parfois de façon très importante et d'autres fois moins en raison de l'abandon de la communauté. L'hypothèse selon laquelle l'incapacité survient d'abord dans les tâches difficiles et plus tard dans celles qui sont faciles, et que les incapacités précoces portant sur les tâches difficiles sont relativement modérées alors que les incapacités tardives portant sur des tâches faciles seraient graves, doit encore être prouvée empiriquement.

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