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Estimation of Physical Functional Disabilities and Long-term Care Needs for Patients Under Maintenance Hemodialysis

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Background and Objectives: Physical functional disabilities in hemodialysis (HD) patients may increase their mortality and long-term care needs. The aim of this study was to estimate the changes of proportion for different physical functional disabilities along time after beginning HD and the lifelong care needs.

Methods: We used a population-based cohort consisting of 84,657 incident HD patients in Taiwan between 1998 and 2009 to estimate the survival function and extrapolate to lifetime through a semi-parametric method. The Barthel Index (BI) was used to measure the functional disability levels cross-sectionally in 1334 HD patients recruited from 9 HD centers. A BI score <50 was considered as severe disability. Lifetime care needs were obtained by extrapolating the age-stratified survival functions to lifetime and then multiplying them with proportions of different kinds of functional disabilities over time.

Results: On average, HD patients had at least 6.4, 2.0, and 1.3 years without disability, with moderate disability, and severe disability, respectively. The most common care needs were stair-climbing and bathing, which were 3.0 and 1.7 years, respectively. HD patients were expected to have about 3 years living with disabilities for those beginning HD at an age above 35 years; however, the older the patient, the higher the proportion of functional disabilities and care needs.

Conclusions: HD patients are in need of long-term care and require early intervention and resource planning. The method developed in this study can also be applied to other chronic illnesses with various functional disabilities.

Key Words: hemodialysis, disabilities, long-term care needs

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Treatments and cares for patients with end-stage renal disease (ESRD) are costly and represent potential growing burdens on health care costs worldwide. The number of patients with ESRD in the United States has increased from about 60,000 in 1980 to over half a million in 2010,[1] and it is projected that this number will surpass 785,000 by 2020.[2] These patients typically survive with kidney transplantation (KT) or dialysis therapy, of which hemodialysis (HD) treatment is the most prevalent in the United States. The same trend also exists in Taiwan with an added problem that renal transplantation is less frequently performed because of a shortage of kidney donors. Although dialysis technology improves the life expectancy of people with ESRD, it may also add years of functional disability to these patients, especially for the elderly.[3–6] As the number of long-term survivors of ESRD on maintenance HD increases, nephrologists caring for these patients may face a growing number of physically challenged patients. Patients with chronic kidney disease have reduced physical functioning, which, along with lowered physical activity, results in poor outcomes in patients treated with dialysis.[7–10] Without appropriate long-term management of patients' functional disabilities, there would be a vicious cycle in which the worsened physical functions would increase mortality, morbidity, and long-term care needs. In the "K/DOQI Clinical Practice Guidelines: Cardiovascular Disease in Dialysis Patients,"[11] the National Kidney Foundation Kidney Disease Outcomes Quality Initiative (NKF KDOQI) recommends exercise to improve cardiovascular function; however, it neither includes a comprehensive regular assessment of physical functions, nor is there a routine effort to provide

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TABLE 1. Comparison of Frequency Distributions of Patients Registered as End-stage Renal Disease and Under Maintenance Hemodialysis (HD) for >3 Months and a Cross-sectional Sample From 9 HD Centers in Taiwan

	n (%)		
	Patients Excluded (n = 13,877)	Patients Included (n = 84,657)	Cross-sectional Sample (n = 1334)
Calendar years	1998.1–2009.12	1998.1–2009.12	2012.2–2012.9
Sex (% male)	7122 (51.3)*	41,453 (49.0)	627 (47.0)
Age (y)* (%)			
18–34	92 (0.7)	3818 (4.5)	104 (7.8)
35–49	862 (6.2)	15,846 (18.7)	343 (25.7)
50–64	3984 (28.7)	29,304 (34.6)	487 (36.5)
≥ 65	8939 (64.4)	35,689 (42.2)	400 (30.0)
LE (y) (SD)	5.0 (0.1)	9.7 (0.0)	—
EYLL (y) (SD)	11.8 (0.1)	12.6 (0.0)	—
Median HD duration (y)	2.3	4.3	6.2
Comorbidity* (%)	Before HD	After HD	After HD
Cancer	6943 (50)	8409 (9.9)	69 (5.2)
Stroke	4725 (34.1)	5295 (6.3)	31 (2.3)
Heart failure	2067 (14.9)	3079 (3.6)	29 (2.2)
COPD	1938 (14)	1316 (1.6)	5 (0.4)
Amputation	264 (1.9)	767 (0.9)	28 (2.1)
Total blindness	70 (0.5)	70 (0.1)	8 (0.6)

*$P < 0.005$.

COPD indicates chronic obstructive pulmonary disease; EYLL, expected years of life loss; LE, life expectancy.

interventions for prevention of functional deterioration for systems other than the cardiovascular system.[12–15]

It may be the right time to consider establishing national or international guidelines to integrate a comprehensive program targeting functional disabilities, of which assessing and estimating long-term care needs for HD populations is the first step. Moreover, the establishment of such a program is important for health care policy and resources allocation, especially in an aging society.[6] According to the United Nations, >21% of the world population will be older than age 60 by 2050, compared to 10% in 2000.[16] A rapidly aging population raises questions about the increased burden of ESRD on human life, health care, manpower of care givers, and social welfare. Thus, it is crucial to determine the magnitude of physical functional disabilities and long-term care needs in patients under maintenance HD, which has been and will continue to be the most common therapeutic modality for ESRD. We conducted this study by employing the nationwide database of Taiwan's National Health Insurance (NHI) to obtain the survival function and by collecting a cross-sectional sample from current HD patients to estimate dynamic changes of different physical functional disability states using the Barthel Index (BI). Multiplication of proportions of functional disability with survival probability at each time-point and summing up throughout life provide the estimation of lifelong care needs for such patients.

METHODS

Establishing the HD Patient Cohort

The study commenced after the approval of the Institutional Review Boards (IRB number: A-ER-101-089) of the National Cheng Kung University Hospital. The Taiwan NHI was first established in 1995 and covered 92% of the citizens of Taiwan, which was extended to cover over 99% after 2004. The study was conducted using a secondary database with encrypted identification numbers, of which patients with ESRD (ICD-9 codes: 585) during the period from 1998 to 2009 were recruited from the catastrophic illness registry of the National Health Insurance Research Database (NHIRD) to identify 118,480 patients under HD who were followed until the end of 2010. As all patients with any catastrophic illness can be waived from copayments, the diagnoses must be validated by committees of different medical specialties to prevent any abuse in Taiwan's NHI, including ESRD. These files contained detailed demographic data (including birth date and sex) and information regarding the health care services provided for each patient, including all outpatient visits, hospitalizations, prescriptions, diagnoses, and intervention procedures.[17] The survival after HD for each patient was verified by linkage of NHIRD with the National Mortality Registry database. To assure that the cohort was composed of adult patients under regular maintenance HD, we included patients who were aged 18 years or older, received HD therapy, and survived for >3 months.[18,19] To prevent confounding from other causes that might result in functional disability, we have deliberately excluded 13,877 patients with the following illnesses before beginning dialysis: cancer (50%), stroke (34.1%), chronic heart failure (14.9%), chronic obstructive pulmonary disease (14%), etc., as summarized in Table 1.

Collection of Data of Functional Disability and Disability Levels

We obtained the lifetime survival function from the selected cohort, while we conducted a cross-sectional survey of HD patients to analyze the proportion of disability along different durations after dialysis. From February 2012 to September 2012, all patients from the 9 HD clinics of southern Taiwan were evaluated for functional assessments. In this cross-sectional sample, we also excluded all the aforementioned disorders or treatments (n = 129 patients) that may affect physical functional disability before initiation of HD; among them, there were 47 with cancer, 38 with stroke, 20 with chronic heart failure, 7 with chronic obstructive pulmonary disease, 8 with amputation, and 9 with blindness. Each patient was assessed by the clinician and/or research assistants who were formally trained in evaluating the activities of daily living of every patient, and they determined the BI score.[20] The BI, comprising 10 items with varying weights, has been demonstrated to be a tool with good reliability and validity.[21,22] Two items regarding grooming and bathing were assessed using a 2-point scale (0 and 5 points); 6 items regarding feeding, toilet use, ascending and descending stairs, dressing, controlling bowels, and bladder control were scored on a 3-point scale (0, 5, and 10 points); and 2 items regarding moving from a wheelchair to bed and returning and walking on a level surface were evaluated on a 4-point scale (0, 5, 10, and 15 points). Total possible scores range from 0 to 100, with lower scores representing greater dependency. The BI was classified into 3 categories: no disability (BI: 100), moderate disability (BI: 55–95), and severe disability (BI: ≤ 50).[23] At the same time, we used the original score of each item to estimate detailed, long-term care needs of patients.

Survival Analysis and Extrapolation

Each new patient who fulfilled our inclusion criteria was followed, beginning on the first day of HD treatment and continuing until he/she was deceased or censored on December 31st of 2010. We applied the Kaplan-Meier (K-M) method to estimate survival for HD patients from the onset of HD up to the end of follow-up, namely, 2010, in this study.[24] Because there were many young HD patients in our cohort with a potentially high censor rate, we further employed a semiparametric extrapolation method to estimate the lifelong survival function, which requires only an assumption of constant excess hazards (namely, mortality) to estimate lifelong survival.[25] The estimates were obtained using iSQoL software.[26] The feasibility and accuracy of the methods and software used in this work have been demonstrated in patient cohorts of various illnesses, including stroke,[27] different cancers,[28–30] and patients with ESRD,[31,32] with the relative biases for the estimates of extrapolation being <5%–10%. The above semiparametric method is capable of producing accurate survival extrapolation because it borrows additional information from age-matched and sex-matched referents.[33] The logit transformation of the survival ratio between patients and referents has been shown to be linear over time, which is the key for making accurate extrapolation.[34] We also estimated the expected years of life loss (EYLL), which can be obtained by subtracting the area under the survival curve of HD patients after diagnosis from that of the sex-matched and age-matched reference population in our study.[33] Detailed methods and mathematical proofs are described in our previous studies.[25–34] To empirically validate our method, we have used the proportion of a cohort from 1998 to 2003 for extrapolation to 2010 and compared it with the K-M estimates based on actual follow-up.

Estimation of Lifelong Durations for Different Disability Levels and Long-term Care Needs

The health status of a subject with a specific condition can be classified into k exclusive categories denoted as $H_1, \ldots, H_k$, according to a given measure. The function $P_j(t)$ can be interpreted as the proportion of the surviving subjects whose health statuses are H_j at time t. Hence, the estimation of mean lifelong duration ($\hat{D}_j$) of the population with health status H_j can be obtained by multiplying the estimates of survival probability ($\hat{S}(t)$) with the proportion ($\hat{P}_j(t)$) of a specific health status at time t and then summing up throughout lifetime, that is,

$$\hat{D}_j = \int_0^\infty \hat{S}(t) \times \hat{P}_j(t)\, dt.$$

See Appendix 1 for details of derivation of this formula.

In this study, we applied a kernel smoothing method of averaging the nearest 10% of the observed proportions of living subjects with health status H_j around time t to obtain $\hat{P}_j(t)$ throughout the period from diagnosis to interview (or, duration-to-date),[34] of which the maximum was 30 years. This approach can capture levels of disability among patients who survive during a particular time interval and who are represented among those surveyed cross-sectionally, if it is a random sample and the sample size exceeds 50.[34] Given the analysis based on BI total score, the health status was classified into 3 exclusive categories: disability-free (H_1), moderate disability (H_2), and severe disability (H_3). The expected years of life living with disability (EYLD) can be estimated by subtracting the lifelong duration with disability-free estimate, $\hat{D}_1$, from the estimate of life expectancy of the population, which is equal to $\hat{D}_2 + \hat{D}_3$. The estimates of lifelong duration of disability can be obtained using the free iSQoL software.[26] Similarly, we can obtain estimates of lifelong duration of disability levels determined by the score of an item in BI. For example, the bathing function of a subject was classified into 2 exclusive categories of score: 5 (H_1) and score 0 (H_2).

Statistical Analysis

The differences of age distributions and proportions of comorbidities between HD patients included and excluded in this study and those between included cohort and cross-sectional sample were obtained using the χ^2 test for trend and associations, with $P < 0.05$ regarded as significant. SAS (ver.9.2) software was used in this study.

RESULTS

A total of 84,657 adult HD patients without physical functional disabilities before initiation of HD were included during the study period. The rate of HD patients within this cohort who were censored by the end of the 13-year follow-up was 49.3%. All consecutive patients (N = 1334) under maintenance HD in 9 dialysis centers received the BI assessment under the supervision of their primary care physicians. The median duration from the beginning of maintenance HD treatment to the date of interview was 73.80 months (range, 0.13–357), and the frequency of HD per week was 3 times. The comparison of the frequency distributions of demographic characteristics are summarized in Table 1, which shows that the sex distributions of the smaller sample interviewed at the HD clinics were similar to the national data, but the ages were generally slightly younger. Although the interviewed sample seems to be composed of a higher proportion of patients with a younger age, all the sample sizes of different age groups are >100, which would be sufficiently large for estimation of changes of functional disabilities along durations-to-date. As only 6 of the 1340 patients of the 9 HD centers failed to be interviewed, the response rate was 99.6%. On average, patients under maintenance HD had 6.4 (± 0.1) years without disability, which is the area under the survival curve after adjustment with the proportion of disability, as shown in Appendix 2.

We stratified our cohort into 4 age groups (18–34, 35–49, 50–64, and ≥65) and used the first 6-year follow-up period for extrapolation to a 13-year period. By using the actual K-M estimates of a 13-year follow-up period as the gold standard, we calculated the relative bias (RB) of those extrapolated by our method: RB = (estimate from extrapolation − K-M estimate)/K-M estimate. The results were −2.1%, −3.0%, −4.4%, and −0.6%, accordingly for the 4 age groups.

The proportions of physical functional disabilities among patients under maintenance HD with an individual BI item (eg, feeding, transfer, bathing, etc.) scored as 0, which is equivalent to severe disability, were plotted against time after diagnosis (Fig. 1), and the lifelong durations for care needs of different functional items in BI are summarized in Table 2. For example, the lifelong duration of 3.0 years for assistance in stair-climbing means 1.4 years of moderate disability plus 1.6 years of severe disability for assistance in stair-climbing. Another common care need was 1.7 years for bathing. Table 3 summarizes the lifetime durations with moderate disability and severe disability as measured by BI and stratified by sex and/or age. The younger the age of starting HD, the more the EYLL were noted (Table 3). Although old patients showed higher proportions of functional disabilities, HD patients were expected to have about 3 years of living with disabilities for all age subgroups above 35 years (Fig. 2).

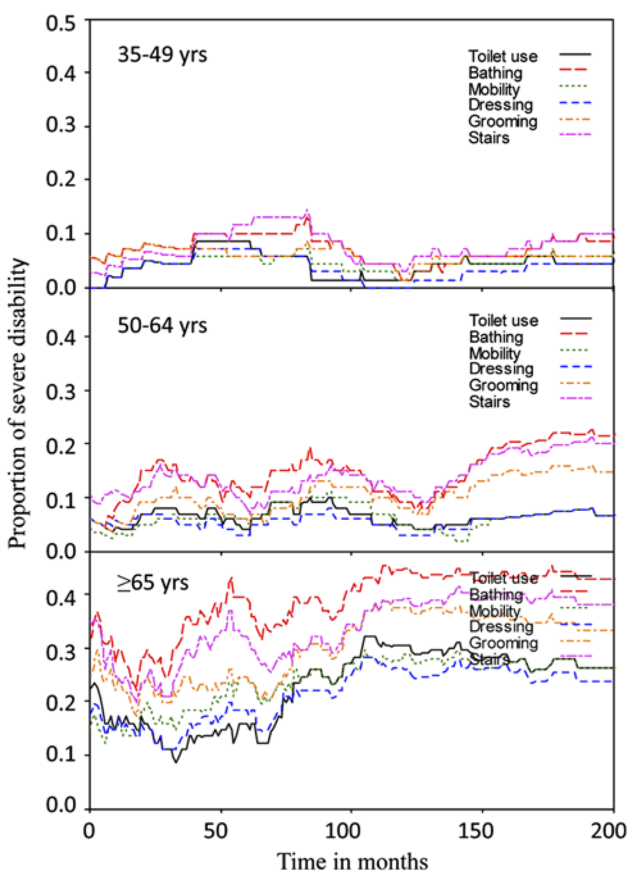

FIGURE 1. Dynamic change in different functional needs for caring for patients with severe disability after hemodialysis stratified by age. full color online

DISCUSSION

In an ideal condition, all the functional measurements would be performed for every subject with ESRD and followed longitudinally throughout life; however, one must wait for several decades for all patients to become deceased to complete such a study. We took an alternative approach to recruit cross-sectional, consecutive patients from 9 HD clinics by assuming that they were randomly drawn from all the prevalent HD patients.[34] As the coverage rate of the NHI of Taiwan has been over 99%, all patients with ESRD were waived from any copayment, and the follow-up period of this study was over 13 years for new HD patients of Taiwan, our original cohort can represent all HD patients in Taiwan. To prevent confounding from preexisting disabilities, we excluded all cases with disorders or treatments that might affect physical functional disability before commencing HD therapy (Table 1). As physical functional disabilities were directly assessed for 99.6% of all prevalent HD patients in the 9 HD centers, and there has been no major change in HD policy, we, therefore, tentatively conclude that HD patients were expected to have had at least 3 years of living with disabilities in their life across all age groups above 35 years. Moreover, older age groups showed higher proportions of functional disabilities (Figs. 1, 2), suggesting that an aging dialysis population would likely produce a heavier long-term care burden for the society. Thus, this study provides the first summary data of dynamic changes (Fig. 1) and the lifelong durations (Tables 2, 3) of different physical functional disability levels for HD patients after excluding preexisting comorbidities that may result in disability, which could be considered as a lower bound for planning service needs. Such estimations may be useful not only for preparing the patient's family for prognosis but also for national resource planning of long-term care after taking age-specific incidence rates of HD patients into account.

However, our results might not be directly generalized to the US and EU countries because of different patient characteristics, medical policy, and financial issues. For example, although the age distribution of incident cases with ESRD between the United States and Taiwan were similar in 2007 (Supplementary Table S1, Supplemental Digital Content 1, http://links.lww.com/MLR/A611),[2,35,36] those in

TABLE 2. Mean (± SE, in years) Lifelong Duration Under Different Levels and Types of Functional Disabilities, as Measured by the Barthel Index (BI)*, Stratified by Sex and Age

		Sex		Age			
Item and Category of BI*	**All (n = 1334)**	**Male (n = 627)**	**Female (n = 707)**	**18–34 y (n = 104)**	**35–49 y (n = 343)**	**50–64 y (n = 487)**	**≥ 65 y (n = 400)**
Feeding							
10	8.5 ± 0.1	8.5 ± 0.1	8.6 ± 0.2	23.5 ± 0.3	16.2 ± 0.3	8.7 ± 0.1	3.9 ± 0.1
5	0.8 ± 0.1	0.5 ± 0.1	1.1 ± 0.1	0.3 ± 0.2	0.8 ± 0.2	0.6 ± 0.1	0.8 ± 0.1
0	0.4 ± 0.1	0.3 ± 0.1	0.5 ± 0.1	0 ± 0	0.2 ± 0.1	0.4 ± 0.1	0.5 ± 0.1
Transfer							
15	7 ± 0.1	7.1 ± 0.2	6.9 ± 0.2	22.7 ± 0.5	14.7 ± 0.4	7.4 ± 0.2	2.5 ± 0.2
10	1.3 ± 0.1	1.1 ± 0.1	1.6 ± 0.1	1.1 ± 0.4	1.1 ± 0.2	1.2 ± 0.1	1.4 ± 0.1
5	0.7 ± 0.1	0.5 ± 0.1	0.9 ± 0.1	0.1 ± 0.2	1 ± 0.3	0.7 ± 0.1	0.6 ± 0.1
0	0.6 ± 0.1	0.5 ± 0.1	0.8 ± 0.1	0 ± 0	0.5 ± 0.2	0.5 ± 0.1	0.8 ± 0.1
Toilet use							
10	7.7 ± 0.1	7.7 ± 0.2	7.7 ± 0.2	23.5 ± 0.2	15.4 ± 0.3	8 ± 0.2	3.2 ± 0.1
5	1.1 ± 0.1	0.8 ± 0.1	1.5 ± 0.1	0.3 ± 0.2	1.1 ± 0.3	1.1 ± 0.1	1.1 ± 0.1
0	0.8 ± 0.1	0.7 ± 0.1	1 ± 0.1	0 ± 0	0.8 ± 0.2	0.6 ± 0.1	1 ± 0.1
Bathing							
5	8 ± 0.1	8 ± 0.1	8 ± 0.2	23.4 ± 0.2	15.6 ± 0.3	8.3 ± 0.2	3.5 ± 0.1
0	1.7 ± 0.1	1.3 ± 0.1	2.2 ± 0.2	0.3 ± 0.2	1.7 ± 0.3	1.4 ± 0.2	1.8 ± 0.1
Mobility							
15	7.1 ± 0.1	7.3 ± 0.2	7 ± 0.2	22.8 ± 0.5	14.9 ± 0.4	7.3 ± 0.2	2.8 ± 0.1
10	1.4 ± 0.1	1.2 ± 0.1	1.6 ± 0.2	0.8 ± 0.4	1.4 ± 0.3	1.4 ± 0.2	1.2 ± 0.1
5	0.3 ± 0	0.3 ± 0.1	0.3 ± 0.1	0 ± 0	0.2 ± 0.1	0.3 ± 0.1	0.2 ± 0.1
0	0.9 ± 0.1	0.6 ± 0.1	1.2 ± 0.1	0.1 ± 0.2	0.8 ± 0.2	0.6 ± 0.1	1.1 ± 0.1
Dressing							
10	7.7 ± 0.1	7.7 ± 0.1	7.8 ± 0.2	23.2 ± 0.4	15 ± 0.4	8.1 ± 0.2	3.2 ± 0.1
5	1.2 ± 0.1	1 ± 0.1	1.4 ± 0.1	0.6 ± 0.4	1.6 ± 0.3	1 ± 0.2	1.1 ± 0.1
0	0.8 ± 0.1	0.6 ± 0.1	1 ± 0.1	0 ± 0	0.6 ± 0.2	0.6 ± 0.1	1 ± 0.1
Grooming							
5	8.5 ± 0.1	8.3 ± 0.1	8.7 ± 0.2	23.4 ± 0.2	16.1 ± 0.3	8.7 ± 0.1	3.9 ± 0.1
0	1.2 ± 0.1	1 ± 0.1	1.5 ± 0.2	0.3 ± 0.2	1.2 ± 0.3	1 ± 0.1	1.4 ± 0.1
Stairs							
10	6.7 ± 0.1	6.9 ± 0.2	7.2 ± 0.2	22.1 ± 0.5	14.5 ± 0.4	7 ± 0.2	2.4 ± 0.1
5	1.4 ± 0.1	1.1 ± 0.1	1.7 ± 0.2	1.1 ± 0.4	1 ± 0.2	1.3 ± 0.2	1.3 ± 0.1
0	1.6 ± 0.1	1.3 ± 0.1	2.1 ± 0.2	0.5 ± 0.4	1.7 ± 0.3	1.4 ± 0.2	1.6 ± 0.1
Bowels							
10	8.2 ± 0.1	8 ± 0.1	8.4 ± 0.2	23.5 ± 0.2	15.7 ± 0.3	8.5 ± 0.2	3.6 ± 0.1
5	0.8 ± 0.1	0.8 ± 0.1	1 ± 0.1	0.2 ± 0.1	0.9 ± 0.3	0.7 ± 0.1	0.9 ± 0.1
0	0.6 ± 0.1	0.5 ± 0.1	0.8 ± 0.1	0.1 ± 0.1	0.6 ± 0.2	0.4 ± 0.1	0.8 ± 0.1
Bladder							
10	8.3 ± 0.1	8.1 ± 0.1	8.4 ± 0.2	23.6 ± 0.2	16.1 ± 0.3	8.6 ± 0.1	3.7 ± 0.1
5	0.8 ± 0.1	0.7 ± 0.1	0.9 ± 0.1	0 ± 0	0.8 ± 0.2	0.6 ± 0.1	0.9 ± 0.1
0	0.6 ± 0.1	0.4 ± 0.1	0.8 ± 0.1	0.1 ± 0.2	0.4 ± 0.1	0.5 ± 0.1	0.7 ± 0.1

*Scaling ranges: 0 and 5 points for grooming and bathing; 0, 5, and 10 points for feeding, toilet use, stairs, dressing, bowels, and bladder; 0, 5, 10, and 15 points for transfer and mobility.

TABLE 3. Estimation of Lifelong Duration (Mean ± SE, in Years) of Each Functional Disability State as Measured by the Barthel Index (BI), Loss of Life Expectancy (LE), Expected Years of Life Lost (EYLL), and Expected Years of Living With Disability (EYLD), Stratified by Sex and Age

		Sex		Age			
	All Patients (n = 1334)	**Male (n = 627)**	**Female (n = 707)**	**18–34 y (n = 104)**	**35–49 y (n = 343)**	**50–64 y (n = 487)**	**≥ 65 y (n = 400)**
LE	9.7 ± 0.0	9.3 ± 0.0	10.2 ± 0.0	23.6 ± 0.0	17.3 ± 0.0	9.7 ± 0.0	5.3 ± 0.0
EYLL	12.6 ± 0.1	12.3 ± 0.0	12.7 ± 0.0	25.2 ± 0.1	18.2 ± 0.0	14 ± 0	6.9 ± 0.0
Years with no disability (BI = 100, % subjects)	6.4 ± 0.1 (65.5)	6.6 ± 0.2 (69.7)	6.2 ± 0.2 (61.8)	21.6 ± 0.6 (90.4)	14 ± 0.4 (82.8)	6.6 ± 0.2 (69.6)	2.1 ± 0.1 (39.3)
Years with moderate disability (BI: 55–95, % subjects)	2.0 ± 0.1 (20.5)	1.7 ± 0.2 (19.3)	2.3 ± 0.2 (21.5)	1.9 ± 0.7 (8.7)	1.9 ± 0.4 (9.9)	2.0 ± 0.2 (19.7)	1.8 ± 0.1 (33.5)
Years with severe disability (BI: ≤ 50, % subjects)	1.3 ± 0.1 (14.0)	1.0 ± 0.1 (11.0)	1.7 ± 0.2 (16.7)	0.1 ± 0.1 (0.9)	1.4 ± 0.3 (7.3)	1.1 ± 0.1 (10.7)	1.4 ± 0.1 (27.2)
EYLD	3.3	2.7	4.0	2.0	3.3	3.1	3.2

Taiwan appeared to have a smaller proportion of males (49.5% vs. 56%), poorer kidney function, less likelihood of receiving KT, but lower 1-year crude mortality, whereas data collected from prevalent cases of North America during 2005–2008 were found to be younger than those in Taiwan and have higher proportions of comorbidities of hypertension, ischemic heart disease, peripheral arterial disease and other vascular diseases, malignancy, and lung disease (Supplementary Table S2, Supplemental Digital Content 1, http://links.lww.com/MLR/A611).[37] Thus, we suspect their needs for long-term care would be higher than those in Taiwan.

In this study's population, the most common needs for assistance throughout lifetime were stair-climbing and bathing, which were 3.0 years and 1.7 years, respectively (Table 2). This is likely because of their muscle strength and usual oxygen delivery being poor,[3] which corroborates a previous study conducted by Cook and Jassal[6] on the higher proportion of dependency in these 2 items. HD patients over 65 years of age seemed to show a decrease in many functional disabilities related to self-care after initiation of HD therapy and reached a nadir by the end of the second year (Fig. 1). A further analysis found mortality rate stabilized after a small initial surge during the first year (Supplementary Figure S1, Supplemental Digital Content 2, http://links.lww.com/MLR/A612), which seems to correspond to the reduced functional disability after commencing HD therapy for those who survived (Fig. 1). Thereafter, the proportion of physical functional disabilities climbed up along with increased age. The up and down patterns for the age group of 50–64 years seemed slower than those of the elderly, with the final climb-up beginning around 11–12 years after HD. For those in the age group of 35–49 years, the proportion of disabilities was usually <10%, but they climbed up about 5 years after HD and then came down. We explored the possible reasons for these phenomena and found that they might be resulted from aging process and complications of ESRD, diabetes, and HD (Supplementary Figure S2, Supplemental Digital Content 3, http://links.lww.com/MLR/A613).[38] These profiles of functional disabilities can help to define relevant preventive and rehabilitation protocols and be integrated into the daily practice in caring for HD patients.

To tackle the high potential of developing functional disability in HD patients, we proposed that a regular screening and exercise program be established for early detection and intervention, especially among the elderly.

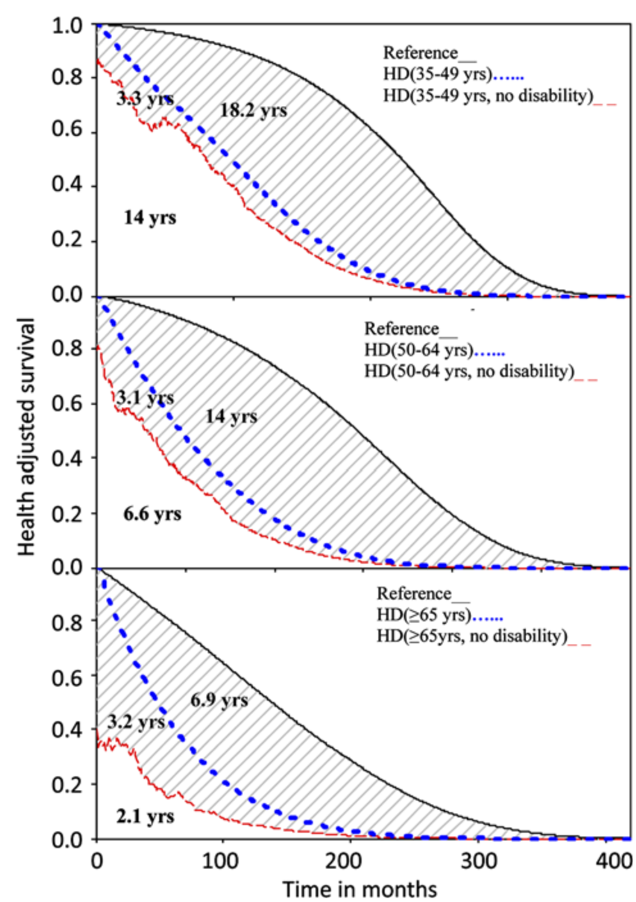

FIGURE 2. The lifetime health-adjusted survival of hemodialysis (HD) patients. Each panel illustrates the sum of expected years of life lost (shaded area between the solid and dotted curves) and the lifespan with functional disabilities (shaded area between the dotted and dashed curves) for HD patients stratified by age. full color online

We may expand the Clinical Practice Guidelines for cardiovascular health recommended by K/DOQI[11] to comprehensively cover musculoskeletal flexibility and endurance,[39] balance, cognition, etc., and consultation with rehabilitation specialists is also recommended for the development of practice guidelines and whenever needed for any given patient. Furthermore, intradialytic exercise training, which has been shown to have positive effects on patients, such as improving cardiorespiratory fitness, physical function, and self reported health,[40] may be considered as there are the conflicts of time in already very busy HD patients.

Potential Limitations

This study has several limitations. First, the censored rate of HD patients within this cohort was 49.3%. Although our extrapolation method theoretically takes care of the issue of estimating life expectancy, we still must assume that these patients would have remained in the same functional state as was measured at the end of the follow-up period. Such an assumption could result in an overestimation in the proportion of patients in good functional states because patients under maintenance HD are usually senior in age and thus, their functional states might gradually decline with increasing comorbidities and advanced age.[41,42] Second, as we applied only BI to assess the functional disabilities (or physical functions of self-care) in this study, we were unable to make any inference on functions related to mental health, for example, cognitive ability, memory functions, etc. Future studies with the inclusion of more detailed evaluation of psychological and other functions, for example, instrumental activities of daily living, would have a more comprehensive understanding of HD patients' disabilities, their determinants,[3] and further long-term care needs, especially among people who begin HD at an elderly age. Finally, this study did not include ESRD patients in Taiwan receiving peritoneal dialysis or KT, which were about 10%–12% and <3%, respectively. The burdens of long-term care needs of these patients, as well as those with modality shifting, will be explored in future studies by our research team. Besides, there has been no home HD program launched in Taiwan; thus, the results of any current study cannot be directly generalized to them.

Conclusions and Policy Implications

This study has successfully estimated the change of proportions for different functional states along time after beginning HD and the lifelong needs for such care. The younger the age of starting HD, the more the EYLL were noted, but the EYLDs of different age groups do not seem to vary to a large extent (Table 3). On the basis of theses evidence, we recommend that regular assessment of physical function and implementation of cost-effective rehabilitation and prevention programs for functional disabilities, similar to program for proactive prevention of cardiovascular diseases, should be integrated into the daily care of patients under maintenance HD.[3,12] Moreover, given the methodology, we shall be able to further estimate the durations of other types of functional disabilities and lifetime expenditures of long-term care for patients under maintenance HD and peritoneal dialysis, and other chronic diseases.

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APPENDIX 1

Estimation of expected durations of patients living with levels of disability after diagnosis:

Suppose that a patient's disability severity can be classified into J levels. Patients' disability levels often vary across their survival times after diagnoses. We can describe the variation for the i-th subject whose disability level is j at time t with the function $q_i(t) = j$, for $j = 1, 2, \ldots, j$ and $q_i(t) = 0$ for $t > T_i$ the subject's survival time. The subject's survival time is a sum of durations of living with the J levels of disability, that is $T_i = T_{i1} + \ + T_{ij}$, where

$$T_{ij} = \int_0^{T_i} I(q_i(t) = j)\, dt = \int_0^{\infty} I(q_i(t) = j)\, dt,$$

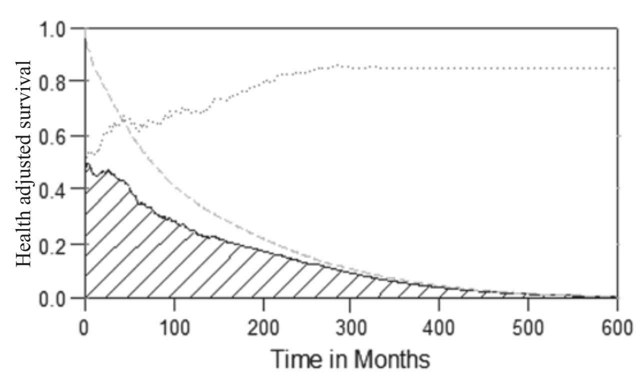
and $I(\cdot)$ is an indicator function.

Suppose that the size of the patient population is N. The expected duration of patients living with disability level j can be derived from the following:

$$\begin{aligned} D_j &= \frac{1}{N}\sum_{i=1}^{N} T_{ij} = \frac{1}{N}\sum_{i=1}^{N}\int_0^{\infty} I(q_i(t))\, dt \\ &= \int_0^{\infty}\left\{\frac{1}{N}\sum_{i=1}^{N} I(q_i(t))\right\} dt \\ &= \int_0^{\infty}\left\{\frac{M(t)}{N}\frac{1}{M(t)}\sum_{i\in G(t)} I(q_i(t) = j) + \frac{1}{N}\sum_{i\notin G(t)} I(q_i(t) = j)\right\} dt \\ &= \int_0^{\infty} S(t)\times P_j(t)\, dt, \end{aligned}$$

where $G(t)$ is the subpopulation of patients still alive at time t, $M(t)$ is the size of the subpopulation. The expected duration can be written as the integration of the survival function $S(t) = \frac{M(t)}{N}$ and $P_j(t) = \frac{1}{M(t)}\sum_{i\in G(t)} I(q_i(t) = j)$ which is a function of proportion of subjects living with j-th disability level at time t. Note that $q_i(t) = 0$ when the i-th subject is dead, and therefore the term $\sum_{i\notin G(t)} I(q_i(t) = j)$ is 0.

APPENDIX 2



The lifetime duration of living without disability for patients with hemodialysis.

The survival probability (dashed line) multiplied by the proportion of patients with no disability (dotted line) over time after diagnosis results in the health-adjusted survival curve (solid line), which can be summed to estimate the expected life years without functional disabilities for patients under maintenance hemodialysis (shaded area).

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