First in line: Prioritizing receipt of Social Security disability benefits based on likelihood of death during adjudication

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Abstract

Background: Given the complexity of the adjudication process and volume of applications to Social Security Administration's (SSA) disability programs, many individuals with serious medical conditions die while awaiting an application decision. Limitations of traditional survival methods called for a new empirical approach to identify conditions resulting in rapid mortality.

Objective: To identify health conditions associated with significantly higher mortality than a key reference group among applicants for SSA disability programs.

Research design: We identified mortality patterns and generated a survival surface for a reference group using conditions already designated for expedited processing. We identified conditions associated with significantly higher mortality than the reference group and prioritized them by the expected likelihood of death during the adjudication process.

Subjects: Administrative records of 29 million Social Security disability applicants, who applied for benefits from 1996 – 2007, were analyzed.

Measures: We computed survival spells from time of onset of disability to death, and from date of application to death. Survival data were organized by entry cohort.

Results: In our sample, we observed that approximately 42,000 applicants died before a decision was made on their disability claims. We identified 24 conditions with survival profiles comparable to the reference group. Applicants with these conditions were not likely to survive adjudication.

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Conclusions: Our approach facilitates ongoing revision of the conditions SSA designates for expedited awards and has applicability to other programs where survival profiles are a consideration.

INTRODUCTION

The Social Security Administration (SSA) operates the nation's two largest disability programs, Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI).[1] As of January 2013, the SSA was providing disability benefits to over 14 million children and adults.[2] This represents over 4% of the U.S. population and accounted for an estimated $200 billion in benefits in 2013.[3] While the SSDI program provides cash benefits and health insurance to workers and their families in the event of a work limiting disability, SSI provides benefits to low income adults and children who are blind, have a disability, or are over the age of 64.[3]

The SSI and SSDI programs are an important safety net to protect people with disabilities. Over time, these programs have experienced a dramatic rise in applications, reaching 3.2 million in 2012,[4] which is roughly equivalent to 25 applications per minute during working hours. At the same time, Federal budget cuts and hiring restrictions in 2011 and 2012 have resulted in attrition of more than 7,000 SSA employees.[5]

As a result of such system pressures, applicants may wait months to years for a final decision. Anecdotal stories of the negative consequences of waiting for a decision abound; applicants have reportedly spent their savings, foregone health care, filed for bankruptcy, lost their homes, and have even died while waiting for a determination about their disability benefits.[6-10] Consequently, streamlining the process and reducing the backlog of claims is a high priority for the SSA, the U.S. Congress, and Americans with disabilities.[5]

Recognizing that rapid disability determinations are crucial for certain individuals, the SSA launched the Compassionate Allowances (CAL) initiative in 2008, the latest of several expedited award initiatives intended to fast-track applicants who clearly meet SSA's disability criteria.[11,12] The CAL initiative identifies the most obvious cases for allowances based on medical information that can be obtained quickly, focusing on "severe and life-threatening conditions."[13] In 2012, the SSA was able to fast-track 6% of its initial applications through their CAL and Quick Disability Determinations processes.[14] Despite this, prolonged determination is still one of the defining characteristics of the process for many applicants.

To achieve its goal of increasing the timeliness and accuracy of the disability determination process, SSA has been steadily increasing the number of CAL conditions since the initiative's inception.[12,13,15-18] Historically, SSA selected CAL conditions based on information received at public outreach, comments received from the Social Security and Disability Determination Service communities, and the counsel of medical and scientific

experts.[11] However, these processes have the potential of biased condition selection, and rare conditions that may not receive public attention could be missed.

To complement the current processes for expanding the number of CAL conditions, we set out to develop a systematic, empirical approach for identifying new conditions to include on the CAL list using SSA's extensive administrative data. This innovative, data-driven approach identifies potential CAL conditions by characterizing condition-specific patterns of death among applicants for SSA disability benefits.

METHODS

Data source

Data were obtained from two sources: 1) a de-identified version of SSA's Disability Research File (DRF), which contained 35.7 million records from the SSDI and SSI programs, and 2) a linked file matching records from the National Health Interview Survey (NHIS) to SSA administrative data and the National Death Index (NDI). The DRF contained applicant information for SSDI and SSI programs from calendar years 1997 to 2006. The NHIS linked files contained SSDI and SSI program applications and participation information, along with data from the NHIS and NDI, in the same time period. The matched NHIS files were used for two purposes: 1) as a nationally representative benchmark to validate the analytical samples derived from the DRF; and 2) as a source of information on cause of death not currently available in the DRF. A detailed description of the NHIS linked files can be found elsewhere.[19,20]

Analytic samples

The NHIS linked file contained data from 22,145 SSDI and 17,480 SSI applicants. For cause of death analyses, we limited our sample to beneficiaries (rather than applicants) since codes indicating the condition/s for which beneficiaries received benefits were only available for this group. The DRF was a claims level file containing 35,795,552 claims for calendar years 1997 to 2006. These claims were associated with 28,849,948 individual applicants (since applicants can have multiple claims). We limited our analytic sample to individuals with a CAL condition that we could identify with specificity (n=510,256) and to individuals with conditions representing 85% of all deaths among applicants who did not have a CAL condition (n=3,007,604). Of these 3,517,860 applicants, we removed duplicates resulting from concurrent applications for SSI and SSDI programs. Thus, our final analytic sample included 2,408,462 individuals. For these individuals, survival times from onset of disability to death, and from date of application to death, were computed. For descriptive purposes, we divided the analytic sample into three groups based on their age at the time of application: children under 18, working age individuals (18-64 years of age), and seniors (65 years of age or older). Working age adults represented the majority of the sample (88.3%) with children representing 11.2% and seniors representing 0.5%.

Identifying CAL conditions

The CAL initiative is based on a list of medical conditions, known as the CAL conditions, obtained through public outreach as well as medical and scientific sources.[11] If an

applicant's medical condition is on this list, their application is expedited and a decision will be received within 21 days. Not all current CAL conditions were identifiable in the DRF since the file predated the CAL initiative. Of the 88 CAL conditions that existed when this study was completed, we identified 24 CAL conditions in the DRF using a variety of information sources. Once these conditions were identified, they served as a reference group for subsequent analyses.

Analytic approach

Our primary outcome was the identification of new candidate conditions for which the risk of immediate death was high. We ascertained death date based on applicant's death year and month provided in the DRF, which originated from SSA administrative records matched to the NDI. We defined survival time as the interval from the date of initial application until the date of death, or until December 31, 2006 (file end date). Since our sample represented a population with a non-homogeneous survival profile, the required assumptions of conventional methods for survival analysis, such as the Kaplan-Meier method, the Cox proportional hazards model, and other modified versions of these estimators, could not be satisfied. Therefore, we developed a new test statistic based on an empirical process of product-limit estimators which addressed the issues of non-homogeneous survival profiles, non-proportional hazards, conditional independence, and progressive censoring.[21]

Survival data were organized by entry cohort **(i.e. date of application)**, and a reference survival surface was constructed using both entry time and survival time for the 24 CAL conditions we identified. This reference surface represented the collective survivability of applicants with these conditions. For each candidate condition, a similar surface was constructed. A test statistic measuring the difference **in volume** between the candidate surface and the reference surface was defined using the respective survival curves and population sizes, weighted according to the random date of application. This statistic was used to test the survival characteristics of each candidate condition against the reference surface. Those conditions for which the test result was significantly lower than the reference surface were identified as CAL candidates (Figure 1).

In addition to the survival surface tests, a ranking method was developed. Each condition in the study was assigned an index defined as the probability that an individual with the given condition would not survive the adjudication process. The empirical distribution of this collection of indices was then considered, and according to cut-off probabilities at 0.975, 0.84, 0.16, and 0.025, conditions were assigned a priority ranking of A, B, C, D, or E respectively. Under a normal distribution, the three-sigma-rule (or 68 - 95 - 99.7 rule) provides a standard for establishing these cut-offs. Though our methods were based on a non-parametric approach, we used these cut-off probabilities since no such values exist for the non-parametric case. Those conditions with a priority ranking of A were 97.5% more likely to die before receiving a decision than all others in our sample. Those conditions with priority ranking B were 84% more likely to die before receiving a decision than all others in our sample, and so on. These priority rankings help identify rare conditions with low prevalence in the applicant pool, where the survival surface test might fail to identify them. They were also used to prioritize potential CAL candidates. All analyses were completed

using Stata 11 and MATLAB R2011. The NIH Office of Human Subjects Research determined that this research was designated as "exempt".

RESULTS

Study Cohort

As shown in **Table 1 a & b**, the median age for applicants less than 18 years of age was under 1 year of age, and the largest group of applicants was working age (18-64). Less than 0.5% of applicants were 65 years of age or older. Applicants in the working age group were predominately men and non-Hispanic White, while older adult applicants were predominantly non-whites. Among adult applicants that did not survive the adjudication process, there was a greater ratio of men to women compared to the ratio among adult applicants that did survive. Over 96% of the study population applied for SSA benefits just once.

In our sample, we observed that 692,837 applicants died, with 41,746 dying before a decision was made on their disability claims (Table 2). Of those that died before receiving a decision, 2,057 were children, 242 were seniors, and 39,447 were working age adults. Working-age applicants had the highest proportion of deaths, followed by applicants age 65 or older and then child applicants.

In the vast majority of cases from the NHIS linked file (71%), the condition documented as the cause of death on the death certificate was the same as the condition cited for disability benefits. In our sample, most deaths occurred following the disability claim decision. In order to receive SSDI benefits, there is a five-month waiting period prior to receipt of cash benefits from the time of the disability onset date. After receiving cash benefits, there is another 24 month wait to be qualified for Medicare coverage. Of all applicants who died (n=692,837), 38% died before they became eligible for Medicare benefits (n=263,009).

Using the survival method described, we identified 24 new potential CAL conditions after comparing the survival time of the top non-CAL conditions leading to death against the collective survival time of individuals with existing CAL conditions. All conditions except two (HIV with nephropathy and chronic liver disease with hepatic encephalopathy) were cancer related. Three conditions were exclusively found in SSDI applicants: (1) lung cancer that is unresectable or with incomplete excision/other histologic types of carcinoma with metastases to hilar lymph nodes, (2) brain or spinal cord cancer, and (3) carcinoma of central nervous system (CNS). Three other conditions were solely found in SSI applicants: (1) carcinoma or sarcoma of skeletal system, (2) recurrent tumor after initial antineoplastic therapy, and (3) HIV with nephrophathy and chronic liver disease with hepatic encephalopathy. (See Supplemental Digital Content Table, Supplemental Appendix A1, for a full listing of the new conditions identified using our survival-based method.)

Table 3 compares mortality among applicants whose conditions were identified through our survival-based method compared to SSA's current method. Overall, applicants with conditions identified using our survival-based method had the highest death rates compared to SSA's current method. For example, using this method we identified 67.9% of applicants

over 65 years of age that died compared to 61.8% percent of those identified by SSA's current method. This result suggests that applicants with the highest risk of death can be consistently identified. The survival method is able to identify conditions with the greatest likelihood of death before a decision is made and, in this regard, is superior to SSA current method.

Table 4 examines the potential impact of the recommended CAL conditions on applicants, including effects on the waiting period from initial application to final decision and on denied applicants. We estimated that on average, applicants whose conditions were identified through the survival-based method can shorten their expected wait time by 1.5 to 3 months depending on the age group.

DISCUSSION

In our sample, we observed that over 690,000 applicants for disability benefits died over the 10 year timeframe of the study, with approximately 42,000 applicants dying before a decision was made on their disability claims. This measure (death before decision) is a function of the high mortality rate of the disease and the speed at which decisions are made. Since the speed at which decisions are made is modifiable, a systematic approach to identify the most deadly conditions is useful for prioritizing conditions for expedited processing. Using the survival method we developed, we identified 24 new potential CAL conditions after comparing the survival time of the highest mortality-related non-CAL conditions to the collective survival time of individuals with existing CAL conditions that we could identify (reference group). Overall, applicants with conditions identified using our method had the highest death rates before and after they received a decision on benefits from SSA compared to SSA's current method. Through the use of an empirical method we demonstrated that applicants with conditions in need of expedited processing can be identified with a reasonable level of accuracy.

We estimated that, on average, applicants whose conditions were identified through our method could shorten their expected wait time by 1.5 to 3 months depending on the age group, representing a relatively small reduction in overall wait time. Thus, healthcare access would be similarly accelerated, although the 24 month waiting period for healthcare benefits would still be applicable to these individuals. Previous research has shown that accelerated healthcare access for SSA beneficiaries led to improved health outcomes, increased health care use, reduced unmet healthcare needs, and encouraged people to look for work.[22-24] These findings suggest that there are clear advantages to earlier receipt of medical benefits for this population. Since these effects were not explored for waiting periods shortened by only a few weeks to months, the effect of expediting CAL cases on these outcomes is not clear.

The large number of deaths observed in our sample is consistent with previous findings indicating that mortality rates are higher among workers with permanent occupational disabilities compared to the general population.[25] In older community dwelling adults, functional status has been shown to be predictive of mortality.[26,27] In fact, functional status has been shown to have a substantial impact on life expectancy, with disability status being

the equivalent of adding ten years to actual age.[28] At any given age, poorer functional status is related to higher mortality.[28] However, the association between functional status and end of life may not be predictable based on the condition leading to death.[29] For instance, individuals with cancer experience varying trajectories of disability during the last year of life.[29,30] If death is thought of as the worst possible outcome on the functional status continuum, this evidence suggests that characterization of functional status, in addition to specification of health conditions and survival characteristics, would enhance the predictive strength of survival analyses such as the one we conducted.

Current methods used by SSA to identify potential CAL conditions include information received through public outreach, SSA communities, as well as medical and scientific sources.[11] These are important processes that serve several purposes. The public and advocacy groups are informed of the CAL initiative, and their expertise is solicited to identify new, potentially rare, life threatening conditions. Highly respected medical and scientific groups are consulted who possess the evidence base for informing decisions about conditions that should be considered for expedited processing. In addition, SSA profits from its own familiarity with case profiles, facilitating recognition of conditions that might be in need of expedited processing. Our analytic methods add value to these existing processes by providing an empirical approach to the identification of potential CAL conditions, thus detecting conditions that might be too rare to reach public attention, where mortality profiles may not be known, or where patterns of death may not be readily apparent. Use of SSA's own administrative data insured that recommendations on potential CAL conditions were of direct relevance to SSA since they reflected the actual SSA applicant pool.

Our analytic method has applicability well beyond the SSA disability programs. The most direct relevance is reflected in the challenges currently faced by the Veterans Administration, where thousands of wounded warriors applying for disability benefits have died while waiting for a disability determination; a source of great public concern.[31-33] Although the health conditions contributing to disability are likely to be markedly different among veterans compared to those applying for SSA disability benefits, our analytic method is of direct applicability to these types of programmatic issues.

The most significant limitation of the study was that the determination criteria used by SSA to classify CAL conditions lacked specificity. For instance, medical listing code 110.08 B (catastrophic congenital abnormalities or disease –attainment of the growth & development level of two years is not expected to occur), was applied to several CAL conditions, including thanatophoric dysplasia (type 1), Ullrich congenital muscular dystrophy, and Walker Warburg Syndrome, making it impossible to identify any of these conditions with specificity. Thus, we could only identify a limited number of existing CAL conditions in the DRF data with certainty and our findings were solely based on the survival surface generated from these identifiable CAL conditions. Over 300,000 deaths were not identified by either the expert-based or survival-based method. Given more specific condition data, we could update the reference group and potentially identify many more conditions warranting expedited processing. Most of the CAL conditions we were able to identify were cancer related. Since the shape of the CAL (reference) region is sensitive to the types of conditions used to generate it, conditions that are found to have significantly worse survival than the

reference conditions could differ as more diverse conditions are included as reference conditions. We did not know cause of death for all applicants in order to verify that deaths were related to the condition for which applicants were seeking disability benefits. However, in the NHIS-SSA linked file, we did know cause of death for beneficiaries. In the vast majority of cases, it was identical to the condition for which beneficiaries received benefits. Finally, this method only focuses on the death of claimants, and does not take into consideration their level of work-related disability. Cases where the onset of a condition leads to profound, rapid, progressive, and permanent functional decline could also be candidates for expedited processing since, although they may survive, their function would not be expected to exceed the threshold necessary for gainful employment.

In summary, through the use of a novel method of survival analysis, we identified 24 conditions where applicants for SSA disability benefits with these conditions would be likely to die during the benefit decision-making process. These conditions were recommended for inclusion on the CAL list and have already been implemented by SSA. This systematic, data-driven approach facilitates ongoing revision of the list of conditions designated for expedited awards and can accommodate changing survival profiles that result from medical advances. We estimate that approximately 87,000 people over a ten-year period will benefit from inclusion in the CAL initiative based on our recommendations. This method has applicability to other programs where survival profiles are a consideration.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

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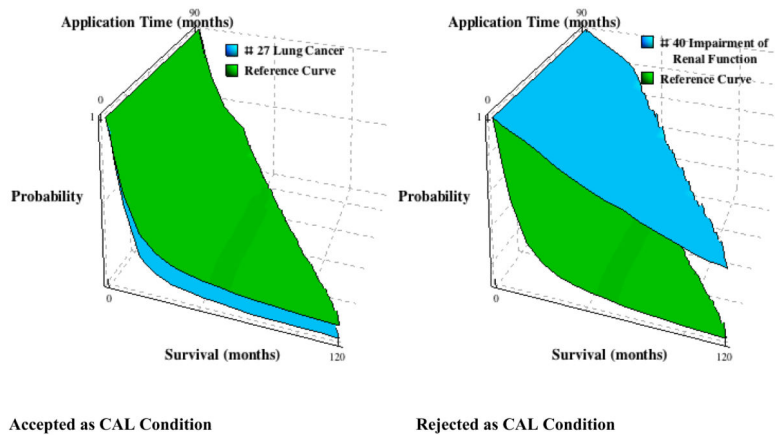**Figure 1.**
Survival surface tests of potential compassionate allowance (CAL) candidate conditions.
Those conditions for which the test result was significantly lower than the reference surface
were identified as CAL candidates.

Table 1a

Demographic characteristics of applicants for SSA disability benefits (1997-2006); Applicants who survived adjudication process (n=2,366,716)[a]

	Age at Application [a]					
	<18		18-64		65+	
	n	%	n	%	n	%
Total	267,398	100.0	2,086,884	100.0	10,749	100.0
Gender						
Male	150,819	56.4	1,127,651	54.0	4,981	43.3
Female	116,579	43.6	959,180	46.0	5,768	53.7
Unknown/missing	0	0.0	53	0.0	0	0.0
Race/Ethnicity						
Non-Hispanic White	47,881	17.9	1,402,604	67.2	2,861	26.6
Non-Hispanic Black	39,281	14.7	421,132	20.2	1,017	9.5
Hispanic	18,250	6.8	131,010	6.3	2,300	21.4
Others [b]	4,235	1.6	90,231	4.3	3,715	34.5
Unknown/missing	157,751	59.0	41,907	2.0	856	8.0
	Median +/− inter-quartile range					
Age at initial application	0.8 (6.6)		48.8 (18.0)		70.2 (10.6)	

Source: NIH tabulation, SSA Administrative Data

[a]: Missing age information (n=1,685);

[b]: Asian, Pacific Islander, Native American, & others;

Table 1b

Demographic characteristics of applicants for SSA disability benefits (1997-2006); Applicants who did not survive adjudication process (n=41,746)

| | Age at Application | | | | | |
| | <18 | | 18-64 | | 65+ | |
	n	%	n	%	n	%
Total	2,057	100.0	39,447	100.0	242	100.0
Gender						
Male	1,171	56.9	24,325	61.7	150	62.0
Female	886	43.1	15,122	38.3	92	38.0
Race/Ethnicity						
Non-Hispanic White	246	12.0	27,373	69.4	107	44.2
Non-Hispanic Black	243	11.8	7,621	19.3	30	12.4
Hispanic	82	4.0	2,224	5.6	45	18.6
Others [a]	25	1.2	1,583	4.1	51	21.1
Unknown/missing	1,461	71.0	646	1.6	9	3.7
	Median +/− inter-quartile range					
Age at initial application	0.1 (0.3)		52.8 (13.0)		65.9 (9.3)	

Source: NIH tabulation, SSA Administrative Data

[a]: Asian, Pacific Islander, Native American, & others

Table 2

Distribution of deaths among applicants for SSA disability benefits (1997-2006)

	Age at Application [a]								
	<18		18-64		65+		Total	
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**
Total applicants	269,455	100.0	2,126,331	100.0	10,991	100.0	2,406,777 [a]	100.00
Died	16,046	6.0	674,352	31.7	2,439	22.2	692,837	28.8
Survived	253,409	94.0	1,451,979	68.3	8,552	77.8	1,713,940	71.2
Total deaths	16,046	100.0	674,352	100.0	2,439	100.0	692,837	100.0
Death occurred before SSA decision	2,057	12.8	39,447	5.9	242	9.9	41,746	6.0
Death occurred after SSA decision	13,989	87.2	634,905	94.2	2,197	90.1	651,091	94.0
Death occurred after SSA decision	13,989	100.0	634,905	100.0	2,197	100.0	651,091	100.0
Before cash benefits [b]	28	0.2	105,596	16.6	128	5.8	105,752	16.2
Before Medicare benefits [b]	126	0.9	262,559	41.4	324	14.8	263,009	40.4
After Medicare benefits [b]	191	1.4	161,997	25.5	305	13.9	162,493	25.0
Deaths among denied applicants	614	4.4	7,396	1.2	102	4.6	8,112	1.2
Deaths among SSI recipients	13,029	93.1	97,313	15.3	1,338	60.9	111,680	17.2
Pending or unknown decision	1	0.0	44	0.0	0	0.0	45	0.0

Source: NIH tabulation, SSA Administrative Data

[a]: Missing age information (n=1,685);

[b]: DI beneficiaries only

Table 3

Identification of deaths through survival-based versus SSA's current methods among applicants for SSA disability benefits (1997-2006)

| Identification Method | Age at Application (n=2,408,462) [a] | | | | | | | | |
| | <18 | | | 18-64 | | | 65+ | | |
	n	Deaths	%	*n*	Deaths	%	*n*	Deaths	%
Survival-based method	176	56	31.8	86,984	75,720	87.1	243	165	67.9
SSA's current method	12,243	1,631	13.3	446,547	321,021	71.9	1,238	765	61.8
Both methods	12,366	1,666	13.5	521,847	388,419	74.4	1,433	930	63.0
Deaths not identified through either method	257,089	14,380	5.6	1,604,484	285,933	17.8	9,558	1,536	16.1

Source: NIH tabulation, SSA Administrative Data

[a]: Missing age information (n=1,685)

Table 4

Impact of adding CAL conditions identified by survival-based method over a ten year period (1997-2006) (n=87,462)

Age at Application [a]	<18		18-64		65+	
	n	**%**	**n**	**%**	**n**	**%**
Number of applicants affected	176	0.2	86,984	99.5	243	0.3
Number of **denied** applicants who subsequently died	8	0.5	1,618	98.7	14	0.9
	Mean +/− sd					
Mean reduction in wait time Months (sd)	2.9 (2.2)		1.5 (1.9)		1.9 (1.9)	

Source: NIH tabulation, SSA Administrative Data

[a]: Missing age information (n=59)