Disability Determination Process: Compassionate Allowance List

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ABSTRACT

Expanding the Compassionate Allowances List (CAL) is an efficient and effective way of improving the Social Security Administration's (SSA's) disability determination process. In this paper, traumatic brain injuries (TBIs) and fatal familial insomnia (FFI) are evaluated and their qualification for the CAL is assessed. Upon researching TBIs and FFI, two models were created that can be used as a framework for evaluating additional conditions. The first model is based on FFI and can be used when there is little variability in a patient's condition. The second model is based on TBIs and can be used when there is significant variability among patients. This framework will potentially improve the ease and efficiency of the disability determination process for both the patients as well as the SSA.

BACKGROUND

Current ways of assessing disability are complex and time consuming. The long wait time associated with obtaining disability can be particularly troublesome for people with extremely serious medical conditions. To alleviate this problem, the Social Security Administration (SSA) established the Compassionate Allowances List (CAL). The CAL is a way of quickly identifying diseases and other medical conditions that invariably qualify for disability. It is composed of a list of 200 diseases and medical conditions that are "so serious that they obviously meet disability standards" (1).

Conditions are currently added to the CAL through information received from the public, outreach to advocacy groups, comments received from the Social Security and Disability Determination Service communities, counsel from medical and scientific experts and research with the National Institutes of Health (1). Although this model is effective, it is slow to implement and does not address conditions that do not uniformly meet the SSAs definition of disability.

Adding conditions to the CAL would be an efficient way of improving the process and will allow patients suffering from debilitating conditions to quickly access benefits. In this paper we will assess fatal familial insomnia (FFI) and traumatic brain injuries (TBIs) to determine their qualification to be added to the CAL. In determining additional diseases that qualify for disability, a model will be created. This model will provide a framework that will allow additional diseases to be identified quickly and effectively.

FFI was chosen for this assessment because of its obvious debilitating symptoms and as a rare prion disease, it was relatively under-researched. Huntington's disease and Hutchinson-Gilford Progeria syndrome were also initially suggested but, as the SSA had already begun preliminary research on those two conditions, the SSA suggested TBIs as an alternate.

TBIs and FFI are designed to be used as examples and additional diseases can be assessed using the same basic model to determine the extent of disability and eligibility for Social Security benefits and the CAL. This will potentially improve the ease and efficiency of the disability benefits process.

Fatal Familial Insomnia

Disease Description: Fatal Familial Insomnia (FFI) is an autosomal dominant neurodegenerative prion disease. FFI is characterized by severe untreatable insomnia and is caused by a point mutation in which amino acid asparagine is substituted for aspartic acid in the prion protein (PrP) gene (3, 4). The mean age of onset of FFI is 50 years and occurs when a critical amount of PrP is converted into the mutated PrPrs prion protein. FFI is very prevalent in some families and occurs 1 in every 30 million people in the general population (5). FFI can be diagnosed by closely examining a patient's family history along with performing genetic tests (6). There is no cure for FFI, and treatment options are currently very limited and focus primarily on palliative care. Historically, FFI patients have responded poorly to conventional drugs such as benzodiazepines and sedatives (3).

Associated Disability: Chief clinical features of FFI include progressive insomnia, memory impairments, hallucinations, motor system deficits, and sympathetic overdrive including tachycardia, hypertension, and hyperhidrosis. These symptoms occur rapidly and severe memory impairments make it impractical for patients to continue with any substantial or gainful employment. As the disease progresses, patients remain in a permanent confused state resembling dementia, which ultimately leads to death. The mean life span of FFI patients is 18 months after the onset of symptoms. Although the exact cause of death is unknown, it is thought to be a result of the disrupted functions associated with sleep including poor resistance to infection, weight loss, debilitation, and a decline in thyroid hormone (3).

Traumatic Brain Injuries

Disease Description: TBI is an acquired alteration in brain function or brain pathology caused by an external force (7, 8). TBIs usually result from a violent blow or jolt to the head (9). Symptoms of a TBI can be mild, moderate, or severe and vary depending on the injury (7). Common causes of a TBI include falls, vehicle-related collisions, violence, sports injuries and combat injuries including explosive blasts (9). Although medical treatment can do little to reverse the damage caused by the injury, approximately half of TBI patients require surgery to remove or repair hematomas or contusions. The severity of a TBI is typically assessed using a Glasgow Coma Scale (GCS) that rates the patient's eye opening, verbal responses, and motor responses. Although the GCS determines the initial severity of the injury, there is no correlation to the patient's long-term recovery. Treatments for TBIs vary depending on the type of injury and often include rehabilitation (7).

Associated Disability: Disabilities from TBIs vary depending on the severity of the injury, the location of the injury, and the age and general health of the patient (7, 10). Chief clinical features of a TBI include headache, fatigue, sleep disturbances, irritability,

decreased concentration, and speed of thinking, memory deficits, depression, anxiety, nausea and mood swings (8). Additionally, patients may suffer from cognitive deficits, difficulties with sensory processing, personality changes, and difficulties with communication (7).

RESEARCH DESIGN, METHODS AND DATA ANALYSIS

As the literature review above indicates, FFI and TBIs are two vastly different conditions and require two different approaches to determine their eligibility to the CAL. Symptoms of a TBI have significant variance and require a model that addresses the patient-to-patient variability. On the other hand, FFI has little to no variably and a consensus about the patient's disability can be reached through alternate methods.

Fatal Familial Insomnia

Research Design: It was determined through the literature review that FFI was a medical condition so serious that it clearly met the SSA standards of disability. This was then confirmed by consulting key opinion leaders (KOLs). According to the SSA, a person would be considered disabled and eligible for benefits if:

- You cannot do work that you did before;
- We decide that you cannot adjust to other work because of your medical condition(s); **and**
- Your disability has lasted or is expected to last for at least one year or to result in death.

Additionally, Social Security pays only for total disability. No benefits are payable for partial disability or for short-term disability. (2)

Each of these criteria was assessed individually. After conducting an extensive literature review and interviewing KOLs, it was apparent that the severe memory and cognitive impairments associated with FFI make it impractical for patients to continue with any substantial or gainful employment. With a mean lifespan of 18 months, no cure or treatment and a uniformly fatal diagnosis, it was determined that FFI was neither a short-term disability nor a partial disability.

These initial assessments were then confirmed after interviewing KOLs, Dr. Pierluigi Gambetti and author D.T. Max. Max was identified after reading "The Family that Couldn't Sleep: A Medical Mystery," a book about prion diseases, specifically FFI. Max worked closely with Dr. Pierluigi when publishing that book and got us into contact with him. Max was interviewed through a series of emails, and Dr. Pierluigi was interviewed via telephone.

These KOLs not only brought their expertise on FFI, but they also reaffirmed our initial hypothesis that FFI should be added to the CAL. The questions asked to the KOLs

were intended to determine whether FFI patients could continue with previous work or any other substantial work and whether FFI was completely disabling, partially disabling or a short-term disability.

*It should be noted that FFI was added to the CAL on January 1, 2013.

Traumatic Brain Injury

Research Design: After conducting an initial literature review on TBIs, it was determined that unlike FFI, TBIs were not uniformly fatal and disabling. The rate and extent of recovery can be highly variable, and the long-tem outcome is often difficult to predict. We thus determined that a different approach was needed to assess TBIs qualifications for the CAL. To address the wide variety of symptoms and abilities of TBI patients, we distributed a survey to patients and caregivers. The goal of the survey was to either confirm or negate the high variability found in the literature. We felt a survey would provide us with a better picture of TBIs as KOLs may only be accustomed to patients with similar injuries and symptoms. The survey also provides a sample of the range of abilities and symptoms of specific patients, an aspect that is missed by solely relying on KOLs. Prior to distributing the survey, institutional review board (IRB) approval was gained, and an online survey was created. The survey was distributed using Qualtrics, and the goal was to assess a wide variety of patients ability to maintain employment. Additionally, we wanted to determine if their TBI was completely disabling, partially disabling, or a short-term disability.

Patients were recruited through several patient advocacy groups including Operation TBI Freedom, TBI Support, Brain Injury Association of California, TBI-Caregiver Support among others. The surveys were distributed through social media outlets including Facebook and Twitter and advertisements in newsletters. Once the surveys were collected, data review began. Detailed results of the survey can be found in the Results section.

RESULTS

Fatal Familial Insomnia

As the literature review initially suggested, KOLs Dr. Gambetti and D.T. Max, believed that FFI is completely disabling. The first interview was with Dr. Pierluigi Gambetti. Dr. Gambetti is a physician and professor at Case Western University; he is a prion disease specialist and has worked with several FFI patients. Dr. Gambetti stated that he could "hardly think of a patient with any more (of a) disability." Gambetti also stated that FFI is a "devastating disability" and there is no doubt in his mind that FFI patients should be eligible for disability benefits. Finally, when asked if FFI should be labeled as completely disabling, partially disabling, or a short-term disability, Gambetti quickly responded with completely disabling.

Then D.T. Max was interviewed. Max is a staff writer for *The New Yorker* and published a book on FFI titled "The Family That Couldn't Sleep: A Medical Mystery." In preparation for writing his book, Max met and interviewed multiple FFI patients and researchers. Max stated that FFI was "permanently disabling (and that) a person could not work, even if they wanted to."

Dr. Gambetti's and D.T. Max's expert opinions along with the established literature suggest that FFI is completely disabling and is a suitable addition to the CAL.

Traumatic Brain Injury

The following figures are based upon the 51 responses collected from the online TBI survey. The survey was open to both TBI patients and those who are caring for someone with a TBI. Survey responders self-identified as TBI patients or caregivers, and all responders were given the same survey. Caregivers responded on behalf of the patient. Out of the 51 people who responded to the survey, 22 of them were patients currently suffering from a TBI, 22 were caring for someone with a TBI, and 7 did not respond (Figure 1). Although, 51 people submitted the survey, there were consistently 43 to 44 responses for each question. This indicates that certain patients or caregivers skipped multiple questions or submitted a blank survey.



Figure 1. Division of responders to the online survey (n=51).

The average age of responders was 35.4. The youngest patient to respond was 16, and the oldest was 65 (Figure 2).



Figure 2. Age distribution of patients (n=45)

Participants were asked about the patients capabilities/abilities to walk, get in/out of bed or chairs, stand, bath, dress themselves, prepare meals, eat, use the restroom, manage money, use a telephone, use a computer, perform chores including grocery shopping, cleaning, getting the mail etc., drive, use public transportation, and write using a pen or pencil (Figure 3). Patients had notable problems managing money (45.5% of responders cannot manage money without assistance or support and 20.5% were not capable of managing money even with assistance or support); driving (15.9% of responders cannot drive without assistance or support and 36.4% cannot drive, even with assistance or support); and using public transportation (19.0% of responders cannot use public transportation, even with assistance or support). Responders were most capable eating (86.6% of responders could eat without assistance or support); using the restroom (84.4% of responders could use the restroom without assistance or support); and standing (84.4% of responders could stand without assistance or support).



Figure 3. Number of patients who are not capable (green), need assistance/support (red) and capable (blue) of walking (n=45), getting in/out of bed or chairs (n=45), standing (n=45), bathing (n=45), dressing (n=45), preparing meals (n=45), eating (n=45), using the restroom (n=44), managing money (n=44), using a telephone (n=44), using a computer (n=44), preforming chores (n=45), driving (n=44), using public transportation (n=42), and writing using a pen or pencil (n=45).

Participants were asked about the patient's level of difficulty getting along with others in social or recreational settings (Figure 4). Of the 44 people that responded to this question: 14 patients had no difficulties, 12 patients had slight difficulties, 16 patients had moderate difficulties and 2 patients had severe difficulties.



Figure 4. Patient's level of difficultly getting along with others in social or recreational settings (n=44).

Participants were asked about the patient's level of difficulty concentrating long enough to complete everyday tasks (Figure 5). Of the 44 people that responded to this question: 5 patients had no difficulties, 11 patients had slight difficulties, 16 patients had moderate difficulties and 12 patients had severe difficulties.



Figure 5. Patient's level of difficultly concentrating long enough to complete everyday tasks (n=44).

Participants were asked about the patient's level of difficulty remembering facts or memories (Figure 6). Of the 44 people that responded to this question: there were no patients that had no difficulties, 11 patients that had slight difficulties, 17 patients that had moderate difficulties and 16 patients that had severe difficulties.



Figure 6. Patient's level of difficultly remembering facts or memories (n=44).

Participants were asked about the patient's level of difficulty coping with day-today stresses (Figure 7). Of the 44 people that responded to this question: there were 2 patients that had no difficulties, 16 patients that had slight difficulties, 15 patients that had moderate difficulties and 11 patients that had severe difficulties.



Figure 7. Patient's level of difficultly coping with day-to-day stresses (n=44).

Participants were asked about the patient's level of difficulty seeing, even with corrective lenses (Figure 7). Of the 44 people that responded to this question: there were 21 patients that had no difficulties, 14 patients that had slight difficulties, 7 patients that had moderate difficulties and 2 patients that had severe difficulties.



Figure 8. Patient's level of difficultly seeing, even with corrective lenses (n=45).

Participants were asked about the patient's level of difficulty hearing, even with corrective aids (Figure 9). Of the 44 people that responded to this question: there were 31 patients that had no difficulties, 10 patients that had slight difficulties, 2 patients that had moderate difficulties and 1 patient that had severe difficulties.



Figure 9. Patient's level of difficultly hearing, even with corrective aids (n=44).

Participants were asked about the patient's level of difficulty making decisions (Figure 10). Of the 44 people that responded to this question: there were 6 patients that had no difficulties, 13 patients that had slight difficulties, 18 patients that had moderate difficulties and 7 patients that had severe difficulties.



Figure 10. Patient's level of difficultly making decisions (n=44).

Participants were asked about the patient's level of difficulty organizing thoughts and ideas (Figure 11). Of the 44 people that responded to this question: there were 3 patients that had no difficulties, 13 patients that had slight difficulties, 16 patients that had moderate difficulties and 12 patients that had severe difficulties.



Figure 11. Patient's level of difficultly organizing thoughts and ideas (n=44).

Participants were asked about the patient's level of difficulty determining risky behavior (Figure 12). Of the 44 people that responded to this question: there were 14 patients that had no difficulties, 15 patients that had slight difficulties, 7 patients that had moderate difficulties and 8 patients that had severe difficulties.



Figure 12. Patient's level of difficultly determining risky behavior (n=44).

Participants were asked about the patient's level of difficulty controlling verbal or physical outburst (Figure 13). Of the 44 people that responded to this question: there were 13 patients that had no difficulties, 13 patients that had slight difficulties, 12 patients that had moderate difficulties and 6 patients that had severe difficulties.



Figure 13. Patient's level of difficultly controlling verbal or physical outbursts (n=44).

Participants were asked about the patient's level of difficulty with their hand-eye coordination (Figure 14). Of the 44 people that responded to this question: there were 17 patients that had no difficulties, 18 patients that had slight difficulties, 8 patients that had moderate difficulties and no patients that had severe difficulties.



Figure 14. Patient's level of difficultly with hand-eye coordination (n=44).

Participants were asked about the patient's level of difficulty interpreting others thoughts (Figure 15). Of the 44 people that responded to this question: there were 7 patients that had no difficulties, 11 patients that had slight difficulties, 20 patients that had moderate difficulties and 6 patients that had severe difficulties.



Figure 15. Patient's level of difficultly interpreting others thoughts (n=44).

Participants were asked about their experiences with depression, anxiety, nausea, hallucinations, disorientation, confusion, irrational thoughts or fears, headaches, dizziness, inaccurate self-image, mood swings, lack of empathy for others and nightmares (Figure 15).



Figure 16. Number of patients who experience depression (n=44), anxiety (n=44), nausea (n=44), hallucinations (n=42), disorientation (n=43), confusion (n=44), irrational thoughts or fears (n=44), headaches (n=44), dizziness (n=43), inaccurate self-image (n=44), mood swings (n=43), lack of empathy for others (n=44) and nightmares (n=44).

Finally, responders were asked if there was expected significant improvement in their condition (Figure 16). Out of the 43 responders, 23 expected significant improvement and 20 did not.





Results from the survey indicate that there is too much variability among patients to strictly label the condition as partially disabling, completely disabling or a short-term disability. For example some responders have severe difficulties with concentration, memory, organizing thoughts, walking, using a computer and have no expected significant improvement. It would be very difficult for these patients to maintain employment and they would eligible for Social Security benefits. On the other hand, there were responders who had no difficulties with cognitive or physical tasks and expect significant improvement in their condition. These patients would most likely not meet SSAs definition of disability and could continue with work.

The variability seen through the survey along with the established literature suggest that without dividing TBIs into subgroups, they are not a suitable addition to the CAL.

DISCUSSION

Based upon the analysis of FFI and TBIs, two frameworks have been created for two different conditions. The first is for a condition where there is little to no variability in all patients diagnosed with that specific condition. This model was based upon FFI, where all patients are unable to continue with any gainful or substantial employment. There is almost no variability among FFI patients and FFI is uniformly fatal. In this situation, there is no need to distribute surveys and information can be collected through an extensive literature review and interviews with KOLs. Literature research can be conducted through PubMed, National Institute of Health, the National Organization of Rare Disorders among others. KOLs can be interviewed through Genetic Alliance, patient advocacy groups and Universities. The objective of interviewing KOLs should be to get their opinions on the severity of the condition and whether it could be labeled as completely disabling, partially disabling, or a short-term disability. It should also be determined whether patients with this condition could continue with employment. If it can be determined from the literature that there is little to no condition variability and KOLs confirm that the condition is completely disabling, that condition can be eligible for addition to the CAL.

The second framework is designed for conditions that have large variability. This framework is based upon TBIs, where the condition ranges from completely disabling to a short-term disability. In this model, IRB approval needs to be gained and surveys need to be distributed to get a better understanding of patient's conditions. Surveys will be disturbed to patients and patient caregivers who will answer specific questions regarding their current health status. These questions will revolve around their ability to perform past relevant work or any other substantial gainful work that currently exists. The surveys can be distributed through a variety of sources including patient advocacy groups. Once the surveys have been collected, data review can begin. Data review will consist of compiling information from the published literature, KOLs and survey results. If the data review determines that the condition is completely disabling and patients cannot continue with employment, the condition can be eligible for addition to the CAL. Dividing TBIs into subgroups, potentially adding certain subgroups to the CAL would be of interest for future study.

Based upon this study, FFI is eligible for addition to the CAL. TBIs however have too much variability to be labeled as completely disabling and thus cannot be added to the CAL. Although the literature research confirms this variability, the survey does have limitations. For example, this online survey was only accessible for patients and caregivers who had access to a computer. This limits the research, for patients whose condition prevents them from using the computer or those who do not have access to a computer did not have an opportunity to participate in this survey. Additionally, the technology used to distribute the surveys (Qualtrics) does not have the ability to distinguish between the responses collected from caretakers and the responses collected from patients. Furthermore, individual responses could not be grouped together and it thus was not clear whether there were people who had multiple functional deficits and others with no overlapping functional problems. Further research should be aimed at more strictly defining TBIs so patients who are severely disabled can efficiently access the benefits they both need and deserve.

CONCLUSION

Although disability determinations are made based on more than just the medical impairments, adding additional diseases to the CAL will reduce some the barriers that many face when applying for disability benefits. After conducting an extensive literature research and interviewing KOLs for FFI, a model was created for conditions with little variance. Using this model, FFI is eligible for the CAL. After preforming a literature review and distributing a survey for TBI patients, a second model was created for

conditions with significant variance. Using this model, TBIs currently have too much variability to be eligible for the CAL. These two models will allow new conditions to be assessed at a faster pace and address the possibilities of conditions that do not uniformly address the SSAs definition of disability. This paper not only determines FFI and TBIs eligibility to the CAL but also establishes two models that can be used to assess future conditions.

Appendix A. Informed Consent given to patients and caregivers



Patient			
Caregiver			
Patients Date of Birth:			
Date of injury/onset of symptoms:			
Briefly describe the injury or initial sym	ptoms before diagnosis:		
Data of diagnosic:			
Date of diagnosis.			
Briefly describe the current treatment of	or therapy the patient is rec	eiving:	
-			
Additional conditions, complications, in	njuries, or medications:		
Additional conditions, complications, in	njuries, or medications:		
Additional conditions, complications, in	njuries, or medications:		
Additional conditions, complications, in	njuries, or medications:		
Additional conditions, complications, in	njuries, or medications:		
Additional conditions, complications, in	njuries, or medications:		
Additional conditions, complications, in	njuries, or medications: or the following tasks: Capable	Need assistance/support	Not capable (even wi assistance)
Additional conditions, complications, in	njuries, or medications: or the following tasks: Capable	Need assistance/support	Not capable (even wi assistance)
Additional conditions, complications, in Please mark the patients capabilities for Walking Getting in/out of bed or chairs	njuries, or medications:	Need assistance/support	Not capable (even wi assistance)
Additional conditions, complications, in Please mark the patients capabilities f Walking Getting in/out of bed or chairs Standing:	njuries, or medications:	Need assistance/support	Not capable (even wi assistance)
Additional conditions, complications, in Please mark the patients capabilities f Walking Getting in/out of bed or chairs Standing: Bathing	njuries, or medications:	Need assistance/support	Not capable (even wi assistance)
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Additional conditions, complications, in Please mark the patients capabilities for Walking Getting in/out of bed or chairs Standing: Bathing Dressing Preparing Meals Eating	njuries, or medications:	Need assistance/support	Not capable (even wi assistance)
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Additional conditions, complications, in Please mark the patients capabilities for Walking Getting in/out of bed or chairs Standing: Bathing Dressing Preparing Meals Eating Using the restroom Managing Money Using a telephone Using a computer Preforming chores including grocery shopping, cleaning, getting mail etc. Driving	njuries, or medications:	Need assistance/support	Not capable (even wi assistance)
Additional conditions, complications, in Please mark the patients capabilities for Walking Getting in/out of bed or chairs Standing: Bathing Dressing Preparing Meals Eating Using the restroom Managing Money Using a telephone Using a computer Preforming chores including grocery shopping, cleaning, getting mail etc. Driving Using public transportation	njuries, or medications:	Need assistance/support	Not capable (even w assistance)
Additional conditions, complications, in Additional conditions, complications, in Additional conditions, complications, in Alexa conditions, in Alexa condition	njuries, or medications:	Need assistance/support	Not capable (even wi assistance)

Appendix B. Survey given to patients and caregivers

Does the patient have difficulties:						
	No Difficulties	Slight Difficulties	Moderate Difficulties	Severe Difficulties		
Getting along with other people in social or recreational settings	0	0	Θ	0		
Concentrating long enough to complete everyday tasks	0	0	0	0		
Remembering facts or memories	0	0	0	0		
Coping with day-to-day stresses	0	0	0	0		
Seeing, even with corrective lenses	0	0	0	0		
Hearing, even with corrective aids	0	0	0	0		
With decision making	0	0	0	0		
Organizing thoughts and ideas	0	0	0	0		
Controlling verbal or physical outbursts	0	0	0	0		
Determining risky behavior	0	0	0	0		
With hand-eye coordination	0	0	0	0		
Expressing your thoughts	0	0	0	0		
Interpreting others thoughts	0	0	0	0		

Does the patient experience?

	Yes	No
Depression	0	0
Anxiety	0	0
Nausea	0	0
Hallucinations	0	0
Disorientation	0	0
Confusion	0	0
Irrational thoughts or fears	0	0
Headaches	0	0
Dizziness	0	0
Inaccurate self-image	0	0
Mood swings	0	0
Lack of empathy for others	0	0
Nightmares	0	0

Has there been a significant improvement in the patients health since initial diagnosis? Please briefly explain.

Is there expected significant improvement in the patients health?

O Yes

O No

>>)

Survey Powered By Qualtrics

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