An Exploratory Study to Assess the Evaluation of Chronic Pain in the Social Security Administration Disability Determination Process[1]

Abstract

This study uses interview data with three populations of actors in the Social Security Administration (SSA) Disability Determination Process (DDP)—claimants, treating physicians, and consultative examiners (CEs)—to assess how chronic pain is evaluated in the DDP. Social Security rulings (SSR), legal and Congressional rulings have attempted to create standardized rules for the evaluation of chronic pain in the DDP; but to date, these regulations are unclear and inconsistently implemented. This study finds that inconsistency is due to a number of factors: the complexity of chronic pain as a component of multimorbidity, medical marginality of chronic pain and multimorbidity, physician and organizational noninvolvement with the DDP, inaccessibility of DDP resources to claimants, and CE bias against perceived subjective evidence. From this data, I make policy recommendations that center around developing targeted resources for the claimant population with complex symptomatology as well as those who must evaluate them.

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> When I read other [physician's] reports, you can see that certain people think everyone is lying. And that's the common thing I see: 'everyone is lying, they're all fakes, they're making it up'… actually most chronic pain patients are thought to be making it up (Dr. K, consultative examiner)
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> The most important part [of the evaluation] is that we have to comment on their functional ability depending on what my impression of the person is. How long do I think they would be able to stand and walk in an 8-hour day, how much weight they can carry…*And that's the part that I think we all need and would use some help with some training*…if there's some sort of parameter, like somebody who has back pain and knee pain and has diabetes and high blood pressure…what's the general consensus? How much could that person do? I bet two different doctors see the patient, depending on that doctor's own biases, would be different…there should be a guideline…like at least 70% probability that another doctor would say the same thing—just something to gauge our impression by...so that we don't have to learn by hit and miss over time. Maybe once in a while the Department of Disability has a training, like a couple of hours training every year, because we need to continue taking CME [continuing medical education]…(Dr. E, consultative examiner, *emphasis added*)

Social Security rulings (SSR), legal and Congressional rulings have attempted to create standardized rules for the evaluation of chronic pain in the DDP; but to date these regulations are unclear and inconsistently implemented. Ongoing court cases substantiate the continuation of inconsistency, institutional inability and/or "nonacquiescence" with such regulation (Masson 1994; Purvis 2011). Bierman (1998) notes that "the subjective nature of pain allegations makes them substantially daunting to assess", which leads to "pain evaluation determinations [being] involved in almost half of the Social Security disability cases pending in the federal court system; such determinations have been noted as the most problematic area in Social Security law."

Due to this difficulty in the Social Security Administration (SSA) evaluation of chronic pain, this study investigates how applicants with chronic pain are evaluated in the disability determination process (DDP) for obtaining Social Security Disability (SSDI). The basis for this research satisfies the Small Grant Program's goal of improving efficiency and simplicity in the DDP by investigating factors in the evaluation of chronic pain that contribute to complexity and inefficiency in the DDP, proposing changes to address this issue, and proposing future research for further investigation. To obtain in-depth exploration of this complex issue, I use a qualitative, case study approach utilizing interviews with claimants, treating physicians, and consultative examiners (CEs). I find several important factors at different levels of analysis that manifest in complexity and inefficiency in DDP evaluation of chronic pain:

1. *Medical Condition Level*: complexity posed by the interaction of chronic pain with other conditions (multimorbidity)
2. *Claimant Level*: inability of claimants to access/understand available application resources, especially pertaining to Listings and medical equivalences
3. *Medical Organization and Physician Level*: marginality of chronic pain and related diagnoses in the medical field, organizational specialization, physician bias, and organizational/physician desire to be uninvolved in DDP
4. *CE Level:* bias, uncertainty and noncompliance with rulings on how to evaluate chronic pain and related diagnoses

Literature Review

From the start of SSDI to the current context, there has not been a clear standard for pain evaluation due to two factors: a) a lack of clarity in modern medicine on how to measure pain using available techniques; b) continued and sometimes conflicting changes in SSA, legal and Congressional rulings, as well as inconsistent implementation from medical adjudicators (Purvis 2011).

Modern medicine has difficulty measuring the location and severity of pain in the body. Many patients complain of pain in multiple, seemingly unrelated places in the body or as 'radiating' throughout the body, which has eluded understanding in medical science for much of the 20th century. However, new medical models connect pain with abnormalities in the neurological, immune, and psychological systems[2], and have stimulated the creation of related diagnoses like fibromyalgia and complex regional pain syndrome, which are both recent listings in SSA regulation. Still, medical technologies for substantiating pain are contested in the medical field, subjectively or objectively. Adjudication between patients' subjective claims of pain are variants on one technique, the visual analog scale (VAS), which shows graphics that may be numerical, drawings of faces, or other visual representations of pain (Breivik, Björnsson, & Skovlund, 2000; Kersten, Kuckdeveci, & Tennant 2012). However, as 2013 SSA DDP Small Grant Fund Winner Anne Skenzich notes, no previous studies substantiate the validity of the visual analogue scale as an objective pain measurement, nor has it been assessed for use in a *chronic* pain population (Skenzich 2014). Commonly used indicators of objective pain measurement are: evidence of muscle deterioration or atrophy (Zieser 1983), weight loss (ibid), sympathetic activation after exercise like tachycardia, increased respiratory rate, hypertension, and increased cortisol (Bruehl et al 1992; Koltyn et al 1996; Wells et al 2008), behaviors like grimacing, moaning, distorted posture, and reluctance to move (Wells et al 2008).

Medical uncertainty and evolving models of pain has manifested in continued changes in SSA, legal and Congressional rulings, as well as inconsistent implementation from medical adjudicators (Purvis 2011). Stimulated by claimant litigation contesting these rulings and implementations, regulations changed from *only* using objective medical evidence as proof of pain, to mandating consideration of subjective testimony *in conjunction* with objective evidence[3]. However, subjective testimony is considered secondarily to objective "accepted medical evidence" (*SSR 16-3p*; Finch 2005). The most recent SSA rulings, beginning in 1996, on the evaluation of chronic pain indicate that any "medically acceptable clinical and laboratory diagnostic techniques, such as evidence of reduced joint motion, muscle spasm, sensory deficit or motor disruption" may be used (SSA *Code of Federal Regulations* 404.1529 2014; *SSR 16-3p*). These rulings make clearer how to evaluate chronic pain in a more broad and inclusive way by considering: 1) an individual's daily activities; 2) the location, duration, frequency, and intensity of pain; 3) factors that precipitate or aggravate the symptoms; 4) the type, dosage, effectiveness, and side effects of medication; 5) treatment other than medication to manage pain; 6) other measures other than medications used to relieve pain (e.g. lying on one side); 7) any other functional restrictions.

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[2] For an overview on old and new models of pain, see DeLeo 2006; Gatchel et al. 2007

[3] For most current ruling, see *SSR 16-3p: Titles II and XVI: Evaluation of Symptoms in Disability Claims* published March 28, 2016

Despite these more clearly defined stipulations, as there lacks consistency and acceptance in the use of medical indicators in the practice of medicine, the use of such techniques and methods for SSA evaluation also lacks consistency and clarity. Continued litigation demonstrates sustained inconsistency in the assessment of pain in the DDP (Purvis 2011; Bierman 1998). In an 8th circuit court case, the SSA "conceded" that "some adjudicators may have misinterpreted" rulings and rejected pain disability claims without consideration of subjective testimony of claimants (Masson 1994). Additionally, court cases identify that privately held biases of medical adjudicators about subjective accounts of pain—especially along the lines of race, class, ethnicity, and gender—have influenced adjudicators decisions (Finch 2005; Purvis 2011). At times, the SSA has even "followed a policy of nonacquiescence, refusing to be bound by federal court decisions beyond the case of the particular litigant" in the evaluation of pain (Masson 1994).

Additionally, chronic pain is only considered to be a symptom that must be part of another "medically determinable impairment" recognized in the "listing" of disabling conditions (*SSR 16-3p*). Though there are many listings in which chronic pain could be a factor, many of these diagnoses have the lowest rates of allowance by the SSA, e.g. carpal tunnel syndrome, rheumatoid arthritis, degenerative disc disease (Meseguer 2013).

Due to such inconsistency, change, and nonacquiescence, it is important to have an in-depth understanding of how chronic pain is currently evaluated in the DDP, which this study undertakes.

Methods

Recruitment: To recruit claimants with chronic pain, a standardized recruitment script for current or former SSDI claimants was sent to all site administrators for chronic pain groups on Meetup.com, which was forwarded to group members if administrators allowed. First, recruitment included all groups in California, and then three months later was expanded to the entire US. Claimant interviewees referred me to their physicians, and both claimants and I both called and emailed recruitment texts to treating physicians. To recruit consultative examiners (CEs), a recruitment script was created in conjunction with contacts at the SSA and forwarded to an East Bay Area CE listserv by SSA contacts. Due to a low (4) number of call backs for CEs, recruitment was expanded to the West Bay Area, but no further CEs responded.

Interviews: For interviews, I used a qualitative, case study approach consisting of twenty-one semi-structured, in-depth interviews [twelve claimants, two treating physicians of claimants, and four CEs] on participants' experiences with the DDP. The case study method involves a small number of interviews and/or observations with actors to gain "depth, multiple perspectives, and process" of an issue (Keen and Packwood 1995; Morrill and Fine 1997). Though this method has been one of the most important methods to study institutional policy since the 1930s, case studies have recently become vital to healthcare and disability research to evaluate health programs and "to shed light on the complex interrelationships among physical impairment, societal barriers, and public programs" (O'Day and Killeen 2002: 444; Keen and Packwood 1995; Crowe et al 2011). Interviews took place either in person, over video call, or phone call. Interviews with claimants began with a description of their conditions, the onset of conditions, their experience with healthcare and the DDP. Interviews with treating physicians focused on how physicians evaluate patients with chronic pain, and their experience helping patients apply for SSDI. Interviews with CEs focused on how they evaluate claimants with chronic pain in their examination.

Analysis: To analyze interview data, I created inductive codes based on questions asked to each population. Triangulation of data between the three populations allowed for thematic codes to emerge that cut across populations, which is how the data is presented in the analytic section.

Data

Sample

The research sample consisted of twelve individuals with chronic pain who have applied for SSDI ('claimants'), four consultative examiners (CEs) who conduct neurological, internal, and/or orthopedic evaluations for the SSA, and two claimants' physicians.

Claimants: Claimants demographics skew towards educated, white women in their 40s and 50s, with only one non-white claimant and one male claimant. The age range of claimants is from late 30s to late 60s. A majority of participants (9) are located in California and applied for SSDI in California due to the fact that recruitment for the study began in California. Many lived in other states prior that are more representative of the country. The remaining three participants represent three other states (Washington, Arizona, and Wisconsin). The educational spread of participants is: one claimant with a high school degree, two with associate's degrees, two with incomplete (non-ongoing) college, four with completed college degrees, and three with completed professional degrees. Work experience and types of work varied across industries and pay grades: e.g. cosmetics salesperson, police dispatcher, bank manager. Prior to their illnesses, five participants identified as middle class, four as upper middle class, one as upper class, one as lower middle class, and one as poor. Important to note is that after their illnesses, ten out of twelve participants experienced downward mobility, with nine identifying as poor, two as middle class, and one as lower middle class.

Consultative Examiners: CEs demographics varied widely, including one Asian, one Black, one Caucasian, and one Middle-Eastern physician, with two male and two female physicians. They range in age between their 40s-50s, and have been CEs in California for over a decade. All CEs conduct at least two different kinds of evaluations, including neurological, internal, and orthopedic evaluations.

Claimant's Physicians: Claimant's physicians were both white males in their 50s. One practices family and sports medicine, and the other practices physical medicine and rehabilitation. Both work at well-known, large medical centers: Scripps and a Kaiser center.

Claimant Medical and Disability Data

Diagnoses

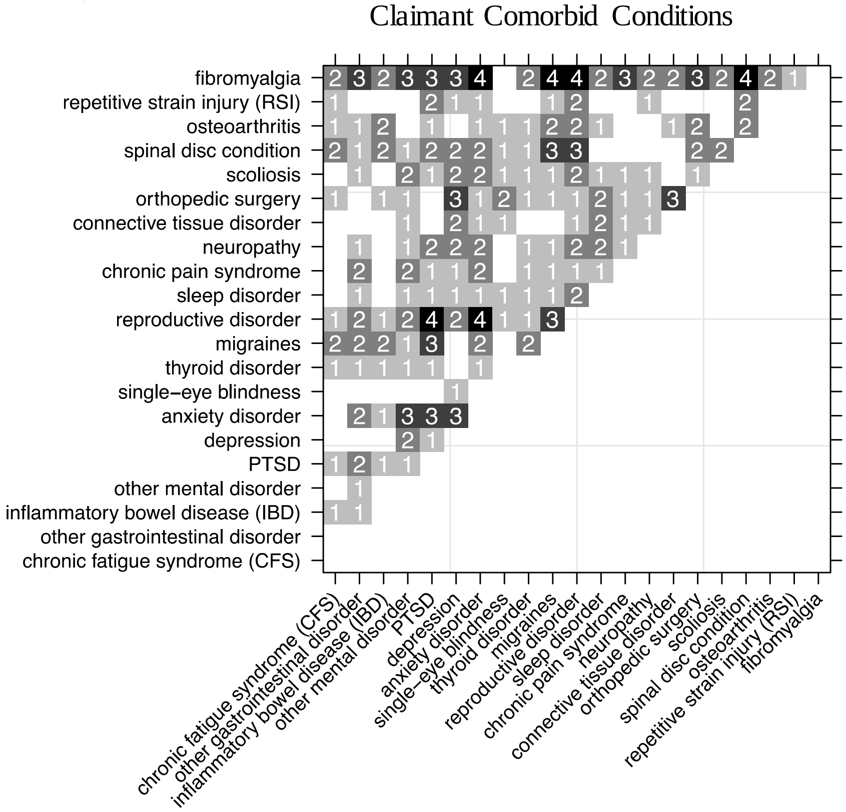

Figure 1: Most frequent comorbid symptoms of claimants. Numbers indicate number of individuals with comorbid conditions listed across x and y axis. Some conditions are collapsed into medical categories that conditions fit under to avoid sparsity.

All claimants have multiple diagnoses (minimum three) that they used to apply for disability, all of which include a chronic pain condition. All claimants have multimorbidities, with eight being the average. The most frequent comorbidities are listed in Figure 1. All participants have multiple orthopedic, rheumatologic, or neurological diagnoses related to chronic pain, with the most frequent diagnoses being: fibromyalgia (8), orthopedic surgery complications (5), migraines (4), thoracic outlet syndrome (3), osteoarthritis (3), neuropathy (3), repetitive strain injuries (RSI) (3), connective tissue disorder (3), scoliosis (3), and sciatica (2). Two claimants have conditions of the reproductive system recognized as causing chronic pain, and five have gastroenterological conditions recognized as causing chronic pain. The most frequently cited symptoms related to chronic pain are fatigue (11), extreme sensitivity to touch (7), immobility (6), swelling (6), cognitive impairment (5), acquired allergies (5), sharp pain (5), shooting pain (5), inflammation (4), burning sensations (3), and pinched nerves (3).

All claimants have diagnoses not categorized as ‘chronic pain’ diagnoses, the most frequent being: psychiatric diagnoses (7), reproductive diagnoses (4), insomnia (4), respiratory diagnoses (3), and chronic fatigue syndrome (CFS) (3). Of the psychiatric diagnoses, depression is most common (5) followed by anxiety (4) and PTSD (4). These diagnoses often interact with or are the onset of chronic conditions/symptoms. A majority of the onset of conditions begins with work pain from either repetitive stress or back/neck pain (7), of which two interact with past trauma/PTSD, and two with subsequent orthopedic surgery complications. The second most common onsets begin with PTSD (4), of which high levels of stress is the trigger of the onset of pain symptoms for two claimants, and two are accompanied by migraines. Two claimants have conditions unrelated to their environment—one genetic and one autoimmune—that cause chronic pain.

The most common diagnoses that interviewed CEs listed overlaps with claimants' reported diagnoses: fibromyalgia, obesity, radiculopathy, neuropathy, back pain, chronic fatigue, generalized chronic pain, and depression. Importantly, two CEs mention seeing a common multimorbid presentation of hypertension, arthritis/chronic pain, diabetes, and obesity, and another CE also added smoking and depression to the grouping. CEs cite a sedentary lifestyle and poverty as the causes of this set of comorbidities.

Medically-Accepted Objective Evidence

Importantly, regarding objective evidence, ten out of twelve claimants have an imaging study (MRI, CAT scan, or X-ray) substantiating their pain, five had at least one orthopedic surgery with complications, all twelve claimants have a prescription history of taking pain medication, and saw physicians specifically for chronic pain (e.g. orthopedists, neurologists, pain management specialists, rheumatologists, physical therapists).

Disability Outcomes

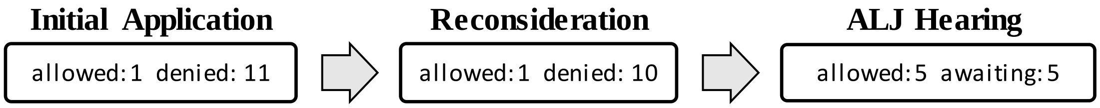

Figure 2: Disability outcomes for claimants.

Figure 2 shows disability outcomes for claimants. Only one claimant (notably the sole male claimant and only claimant who consulted "how to get disability" books before applying) received disability on his first application. The other eleven were denied in their first round, with nine applying without any sort of help and two consulting attorneys, including the claimant who was "allowed" (the SSA's term for being accepted for disability). All claimants were sent to CEs during the determination process. Ten out of eleven were denied in their reconsideration, eight of whom retained legal counsel to aid in this part of the application process. All ten cases were referred to the Administrative Law Judge (ALJ) hearing. All of these claimants retained legal counsel (either lawyers or advocates). Five have been approved in the ALJ hearing, while five are still awaiting their court appearance. Overall, seven of twelve claimants were approved for disability. With the exception of the one claimant who was allowed in the first round (within approximately six months), the determination process took/is taking at least three years for claimants.

Interview Data Analysis

From the interview data, several themes emerged at different levels of analysis that manifest in complexity and inefficiency in the DDP for chronic pain claimants:

1. *Medical Condition Level*: the interaction of chronic pain with other conditions (multimorbidity)

2. *Claimant Level*: inability of claimants to access/understand available application resources, especially pertaining to Listings and medical equivalences
3. *Medical Organization and Physician Level*: marginality of chronic pain and related diagnoses in the medical field, organizational specialization, physician bias, and organizational/physician desire to be uninvolved in DDP
4. *CE Level:* bias, uncertainty and noncompliance with rulings on how to evaluate listings with chronic pain as a component, especially the case of fibromyalgia

1. Medical Condition Level: Multimorbidity

As noted in the sample section, all interviewed claimants have multimorbid conditions (average eight diagnoses), including two or more chronic pain-related diagnoses. CEs confirm seeing the same pattern in their examinations. Claimants feel the complexity of multimorbidity is not understood and therefore dismissed by examiners and adjudicators in the DDP, especially as the extent of their pain is not easily proven using modern medical techniques. As stated in the data section, all claimants have imaging studies and/or orthopedic surgeries as the documented "accepted medical evidence" of severe pain, and all claimants are or have taken pain medication; hence, claimants develop feelings of confusion and antagonism toward the DDP. Therefore, I take the time to explain in full how multimorbidity develops for these claimants, as it forms the context for complexity of evaluating these claimants in the DDP.

For claimants, having many diagnoses is a circumstance that arises over time as pain worsens and spreads, increasingly interacting with other related or unrelated conditions. The onset of multimorbid conditions most often involves the interaction of multiple "triggers", or factors that contribute to either the onset or rapid exacerbation of conditions. Notably, only two claimants had conditions that were not environmentally-caused conditions (e.g. early-emerging hereditary disorder), though both were highly exacerbated by work expectations. For seven of twelve claimants, the principle trigger was work-related pain from repetitive stress and/or spinal pain that was initially localized; an additional claimant's pains were attributable to a work-related accident. Work-related pain comes both from physical- and sedentary-based work. As most claimants formerly had active lifestyles, exercise also became a trigger, to the point where no interviewee is able to exercise beyond short walks. Another common trigger is having past trauma (physical and/or emotional), as four claimants were diagnosed with PTSD prior to any chronic pain problems. Interestingly, treatments for chronic pain are also common triggers, with the three most mentioned being orthopedic surgery, physical therapy, and side-effects of pain medications. Lastly, extreme levels of persistent or situational stress from work or family life act as another trigger for many.

Regardless of whether claimants initially have extreme stress or trauma as triggers, experiences like increasing pain, the onset of other (often seemingly inexplicable) symptoms/conditions, the threat of losing work or actually losing work, and the difficult navigation of healthcare/disability institutions renders these factors as triggers for all claimants sometime in the process. Most claimants are fired from their jobs for their declining performance at work. Claimants often have difficulty contesting the legality of these terminations to the all-encompassing nature of navigating health/disability institutions—which I detail more of later in this section.

There are various physiological processes for how symptoms and conditions connect to one another and become worse for claimants. The two most common that claimants describe are: the onset of inflammation, and neurological dysfunction (neuropathy and/or sensitization) once the pain begins. When these factors do not occur continuously, claimants term their onset a "flare-up". For most claimants, certain movements or exertions are what cause a flare-up—which is why work and physical activity/therapy can be triggers for pain. One claimant describes this process:

> I got hurt in my right arm first, and it was more like classic tendonitis that became chronic and didn't go away. But, it does radiate from different places so it radiates from my elbows - which is why I got the tendonitis diagnosis - and then also from my neck. So I often get neck pain with radiculopathy as a diagnosis. I also believe I was correctly diagnosed with Reflex Sympathetic Dystrophy [RSD]…people who have that kind of nerve damage, they get a longer list of diagnoses…it's so hard to tell, the symptoms overlap. When I flare up: My problems on each side get worse differently. On the right side I have pain that never ever goes away…more like inflammation…the sensitization of the nervous system can flare me up, when I'm cold...The sharp and shooting side is the left side and I feel like the left side was initially an over-compensation injury…it's cumulative trauma…it happens over a period of time and I do think that PTSD creates the initial neural pathways for chronic pain and trauma. So later in life where some people might not get RSD from repetitive strain injury, they might not end up with neuropathy…[.]

Hence, when claimants enter the DDP, they have widespread chronic pain in multiple parts of their bodies, which is initially experienced as more localized and then "radiates" from one locality to another or "comes up" in multiple areas of the body. All claimants' pain is either caused or exacerbated by their work, and therefore localized pain "spreads" to other areas because claimants keep working and "push through" the pain thinking that "it should get better". Claimants "push through" due to fear of being fired from their jobs, along with job-related cultural scripts like "I could just suck it up—a typical law enforcement attitude". These attitudes do not prevent all from seeking medical attention early on, though most wait until the pain is sufficiently severe to interrupt job performance. It is years past this point when interviewees apply for disability, and consequently, the interaction of all such conditions affect all other levels of the DDP.

2. Medical Organization and Physician Level: *Marginality of Chronic Pain and Disability*

The complexity of chronic pain progression and multimorbidity leads claimants to have complex interactions with medical institutions, which affects the complexity and integrity of their applications. This manifests most clearly in the "stack of papers" that constitutes claimants' medical records, which contain many negative tests in the attempts to find adequate measures of a difficult to measure condition (pain), types and numbers of doctors. Most claimants perceive that their medical history results in unwarranted bias and dismissal of their case, as one claimant reasons:

> When disability got my paperwork from Kaiser, the only thing they probably saw was 'oh wow she must have been to 50 million doctors. She must be crazy'.

The structuring of the current healthcare system around physician specialization manifests in interviewees seeing many specialists for diagnosis and treatment. Even for pain alone, claimants see multiple orthopedists specializing in specific body parts, as claimants have severe pain in multiple locations before applying for SSDI. Specialization prevents physicians from seeing the "whole picture" of multimorbidity that amounts to full disability for claimants, as an applicant describes:

> One of the biggest issues I ran upon was when it came to seeing different doctors...they would only look at that one joint or that one specific problem…of course a doctor wouldn't say, 'Well you should go on disability because you have pain in your knee.'

Though general practitioners are the physicians charged with keeping track of the "whole picture" of patients' health, claimants find that they are often unable to do so. Instead, many claimants find that integrative and functional medicine physicians are the only physicians able to help with the entirety of their treatment for multiple conditions, as such physicians are often considered "alternative" by mainstream biomedicine even though they are DOs or MDs, and likewise, as will be discussed in the section on the CE level, CEs do not take these physicians' notes seriously. Claimants also see many physicians because of physician biases against pain conditions that they are "all in their head"—especially from workers' comp physicians—and again, witnessed at the CE level.

Claimants even find difficulty just getting into contact with their numerous doctors—especially those at large medical organizations—which is multiplied over the number of doctors that they see, have to keep track of, and often stay on top of with requests for prescriptions, appointments, and materials for disability applications. My own attempt at physician recruitment validates this difficulty, as I was only able to recruit two claimants' physicians out of the seventeen that both claimants and I repeatedly contacted. As a result, many claimants' files may be incomplete, and all but one seek legal advocates in order to help with this issue. (notably, in exploratory interviews for a new project interviewing disability attorneys, I have an 80% recruitment rate).

Kaiser shows up in several interviews as particularly distressing, and even a claimant who was a nurse at Kaiser left both her job and her care there because she "was being so mistreated within the Kaiser system" after her pain began. The claimant who received SSDI in his first application says he switched doctors *six times* for these reasons, and eventually left Kaiser and paid out of pocket. The next statement from one claimant is illustrative of distress experienced in this process:

> I didn't want to apply for permanent disability because I was still—I still knew that Kaiser hadn't done the things they were supposed to do. I still knew that I was being thrown around and no one was taking responsibility…all you could give them was one piece to the puzzle at a time…you would think disability and not being able to walk would be my primary problem, but my primary problem is Kaiser…the regular doctors like the physical medicine and so forth, want to say that you have a mental problem but when you get to the psychiatry department, they tell you 'no your pain is not associated with any mental issues', so I don't get any help… I asked [my doctor] for a wheelchair and he said, "ask physical medicine". I ask physical medicine, she says, 'ask pain management'. I go to pain management and they say 'well you're seeing us about your back not your legs. You have to go back to physical medicine to get your wheelchair', so I had to buy my wheelchair with my own personal money.

As demonstrated in the above statement, dealing with doctors, medical organizations, and institutions like workers' comp is robustly described as "a full time job" that contributes to further physical and psychological damage, as well as the inability to work, as one interviewee describes:

> I had been in so much pain that I could barely function…I was basically 'constructively fired' because I wasn't working up to par…I had to take a lot of days off because I couldn't move. I've got nine different doctors that I see on a regular basis, so that takes up a lot of time too. There are some times where I spend between 20 to 30 hours a week at medical appointments.

Additionally, even getting medical records successfully sent is an issue for some claimants, and, as will be discussed in the next section, interviewed CEs report not getting claimants' medical records 40-60% of the time—one noting that Kaiser records are missing most frequently.

To their surprise, claimants find that almost all their physicians—even their best and most supportive physicians—are uncomfortable helping them apply for disability. All but one claimants' physicians are uncomfortable due to ignorance about SSDI and the DDP, which creates confusion of what they need to provide in applications and amplifies possible fear about an unknown "bureaucratic" process. Connected to this are misconceptions and biases about "disability"—e.g. that it is "permanent" and recipients don't have to be reviewed after obtaining it. Such misconceptions often lead to active *antagonism* toward the DDP and SSDI. Claimants find that even their most helpful physicians are often unwilling to help them apply because physicians' attitudes toward the DDP and SSDI is that they "keep people sick and disabled". This position is substantiated in my interview with one of their physicians, who states:

> Looking back maybe 15 - 20 years I used to say to people, 'I'm not a disability doctor. I'm an ability doctor…these systems constrain patients. They turn them into people who have to meet criteria…You got to keep proving you're injured–how do you recover from that?…I say to them…do you want to heal or do you want to prove you're sick?...That's the constraint of these systems that put people under these boxes where they have to be one thing or another…

Physicians also have resistance toward the DDP because of time and monetary costs of their participation. These views are reflected in this same physician's statement:

> Years ago, I would sometimes send a summary or whatever with the records. I've kind of gotten tired of doing that, so I just send them whatever they ask for—the records—and they pay a little bit for the records–-a tiny amount. They used to pay a little bit more for the summary, and with cutbacks and things they paid so little it almost wasn't worth the time to write the letter…

As a result, some claimants' physicians pushed costs onto their patients by charging them for letters at as high of a price as $250.

The policies of medical organizations reflect and maintain these attitudes as well. The other physician that I interviewed states that his region of Kaiser (he is not sure if true of other regions) has a policy that physicians cannot help patients apply for disability because "it's not their [physicians'] job, because they only deal with treatment and not medical management. And, it's not considered a covered healthcare benefit" in the Kaiser system. Resultantly, Kaiser will only send medical records. However, as one CE noted receiving medical records the *least* from Kaiser patients, this questions the follow-through on this policy. The claimants' physician does not agree with Kaiser's policy, and writes letters anyway at his own risk of punitive action. Claimants say that this same issue is true of worker's comp.

Medical organizations can also limit what testing is done for evidentiary purposes due to cost. Part of why the first-time disability recipient paid $450 to see an outside 'disability' physician was because Kaiser would not cover the costs of imaging he read was necessary to establish his conditions. Other claimants cited insurance coverage as a barrier to obtaining adequate evidence of their condition.

Such a lack of support from physicians keeps some claimants from applying as long as several years, vastly worsening their condition. All but two claimants apply "completely on [their] own", only requesting medical records and avoiding their physicians altogether, even though outside resources that claimants (eventually) consult state clearly that obtaining doctors' letters are essential to a positive outcome for disability.

Thus, institutional processes within healthcare affect how a patient becomes a claimant. Medical institutions affect the DDP through the sending (or not) of medical records, the compiled content of such records, and the knowledge and willingness of physicians and organizations to participate in the process. As a result of such difficulties, all but one claimant hires legal counsel, as such advocates are the only ones able to get physicians to respond by taking on the labor of repeatedly intervening on claimants' behalf by providing physicians with information on what they need to include in the application. As such, one central finding of this study is that the legal process—through legal advocates and the ALJ—becomes central to the DDP of claimants with chronic pain, rather than the SSA or treating physicians.

3. Claimant Level: Confusion about Application and Available Resources

Throughout the application process, the case of multimorbidity manifests in confusion on what claimants should include in their application, and discrepancies between what evaluators need and what applicants—and their treating physicians—provide. Claimants have many conditions—some of which do not appear as listings—and they are unsure of which to list as primary and how to indicate their relations to one another. None were able to find information on establishing medical equivalences to listings, which would have been helpful more many of their cases. One claimants conveys that, due complexity of her applications and "full-time jobs" as a sick patient, "just writing the forms was exhausting, physically…I did it a piece at a time. I'd do a page, and I literally laid down".

Part of the confusion is due to the fact that ten of twelve applied "completely on [their] own" the first time. Given that there exist resources—including the SSDI application website—to help applicants with the process, I asked why they didn't use these initially. Claimants cite the severity of their pain, high levels of emotional distress, their "full time job" as adjudicators of doctors and medical institutions, and especially, their cognitive impairment (termed "brain fog") resulting from pain, as reasons why they were confused about the availability of resources. These same issues affected their ability to process text resources, especially information on the SSA website. Additionally, most claimants cannot hold books due to pain, so they would have to rely on online resources, and most applicants cite only being able to use computers less than 15 minutes a day due to pain. One claimant noticed the well-defined resources available to blind applicants, and wished that there was similar help for applications with many overlapping, challenging symptoms, like herself. Most did not know that they could get help at the DDS office, but those who were aware were afraid do so due to a perception that these employees had influence over their claim. Many also could not get to the office to obtain help.

Complicating the application process is that for a majority of applicants, SSDI is not their only application process, as they rely on SSI, short-term disability, or workers' comp. One claimant relays the complexity of this situation:

> Work comp cuts you off unexpectedly–they don't tell you they're going to do it, they just don't send you a check. You call them and they say, we think we should be done paying you. And then I called my lawyer and my lawyer has to go fight about it in court and then eventually the judge gave me it like four years later. They cut me off so many times I can't even count. I don't even remember. Many times I thought I was going to go homeless. I didn't know if I was going to have my rent money on any given month because to apply for different programs there's turnaround times--It's a full-time job when you have incapacitating disabilities…I wish there was a streamlined process that qualified multiple agencies, just one application…that would've helped me the most.

After initial denials, all claimants found that textual resources, like 'disabilitysecrets.com', provided more helpful information than the SSA website. Additionally, all but one claimant retained advocates and/or legal counsel. Resources that claimants consulted told them to list certain primary conditions that are more sure to get favorable decisions from the SSA, even if they did not experience those conditions as their primary conditions. Most applicants cite severe chronic pain as the main reason for needing disability, but resources told them that chronic pain had low allowance rates for disability. One applicant, a former police officer, describes the moral conflict she felt:

> [The pain] was so debilitating that I couldn't get up in the morning—and I had to get up in the morning. I was living in my vehicle. So yeah, I did the next best thing. It was so heartbreaking because the system actually caused me to basically lie to the system to get the help that I should have been getting the minute I blew my knee out and things weren't getting better. And that's the thing that I've struggled with the absolute most: here I am in a profession that is based on truth and honesty, and I'm not being 100% honest about that. Because I can't be.

The high denial rate for claimants with chronic pain results in extremely long wait times for applicants to receive response on their application. Of those eleven of twelve denied initially, *all had to or are waiting over three years for disability decisions*. These long wait times are devastating for applicants, and all claimants reported having *no* income that entire time. Claimants go into debt, file bankruptcy, become homeless, or those with family/friends rely on support to not be homeless—though applicants say that this reliance generally strains or destroys these relationships. The devastation extends to their their physical and mental condition because of the stress of their situation and their decreasing ability to be able to afford treatments. Many applicants acquire mental health conditions—including depression, anxiety, and dissociative disorder—during this period.

There are two reasons why applicants have no income: first, because the vast majority are too sick and in so much pain that they cannot work or find a part-time job that could accommodate their limitations (most were fired from more than one position because of their sickness). Second, consulted resources tell claimants that *anything* that they do that indicates possible work functionality will ensure denial for disability. One claimant relates the position this put her in:

> I even shut down my Facebook account for fear that the judge might go home and see what I was doing [running a pain support group] online. I had heard about this lady who was denied because she wrote a blog, and the judge said, 'Well if you can write a blog, you can work.' Well that's just not logical. If I can type in for 15 minutes a day, that does not give me the ability to keep a job …If nothing else, what I would really like to see changed is that during the time that you're waiting to be on disability, you cannot go to school, you can't work, even though now [after getting on disability] I can. During the process, I can't lift a finger…I'm trapped…

For applicants, the DDP adds 'insult to injury', as the difficulties they face in their health and healthcare limit their abilities to apply and compromise their actual application materials. Applicants feel antagonism toward the DDP as intentionally unclear and complex.

4. CE level: Bias, Uncertainty, and Noncompliance

The complexities posed by multimorbidity (especially with hard-to-measure symptoms like chronic pain) and biomedical biases against conditions like fibromyalgia and chronic back pain also manifest in consultative examinations.

Interviewed CEs state that SSA guidebooks provide them with general indications of what the CE report should look like, what terminology to use, and what the SSA wants to know about claimants from an evaluation (though, notably, one CE said he never received any such materials, but only a few example reports from his contracting company). However, CEs say guidebooks are not sufficient for evaluating these complex claimants. The same disadvantages of medical specialization manifest in CEs being reduced to considering chronic pain only within the confines of their given specialized examination, rather than in a patients' context of multimorbidity. They state that they are unsure of how to adjudicate between the notes of the multiplicity of physicians, diagnoses, and treatments that multimorbid patients present. *As evidenced by the quote included at the beginning of this report, the CE, Dr. E*[4]*, clearly requests that CEs get continued medical training by the SSA for evaluating multimorbidity and chronic pain, as guidebooks and training as a medical doctor did not give her the tools to do such evaluations.* Hence, she is "concerned about whether [she] is being fair to patients" as she has to "learn by hit and miss over time".

Due to such discomfort in their own judgment, CEs latch onto what information the guidebooks do present—the centrality of objective evidence; though, CEs uniformly only see *imaging studies* and their *physical examinations* as objective evidence, rather than any other secondary evidence provided in SSA guidebooks. CEs inconsistently consider other indicators from medical records (e.g. lab work, physicians' notes, diagnoses) as untrustworthy due to biases against certain types of physicians and diagnoses. For instance, Dr. P doesn't trust the notes of surgeons and pain doctors because he considers them "doctors who just want somebody to be on narcotics chronically because that's your patient for life". Dr. M only looks at the physician notes that specifically speak about pain, and only "glances over" the notes of physical therapists.

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[4] All gender pronouns for CEs are assigned randomly in order to protect subjects' identities do to the low n for CEs

CEs do not report looking at any "alternative" or "integrative" physician notes because "they do not have the same training", though most integrative physicians do have the same training because they are DOs and MDs.

CEs also have biases against certain diagnoses, like fibromyalgia and chronic fatigue syndrome and the tests done to establish them, especially problematic because a majority of claimants in this study have fibromyalgia and fatigue. Two CEs illustrate in their comments about fibromyalgia:

> I think it's really depression. I really don't think fibromyalgia exists by itself…there's nothing physically definable in fibromyalgia …It's a diagnosis of exclusion. (Dr. P)
>
> My understanding is that [the tender point test] was never meant to be a diagnostic test for fibromyalgia…it's like everything else about fibromyalgia, it's controversial. (Dr. K)

CEs are skeptical of anything they view as "controversial" or "subjective"—regardless of if presented by a claimant or another physician. In the case of fibromyalgia, all CEs do not use the tender point test, the accepted medical technique for evaluating the condition.

Another bias is evident in how CEs independently develop evaluation heuristics based on factors like gender, age, and perceived untrustworthiness of claimants. Dr. E illustrates her heuristics and concerns about them:

> It is very, very subjective and usually with the females I compare them to myself and I don't know if that's the right way because I am a pretty healthy person. I know how much I can carry easily, how long I can carry…and for men…my son and my husband I see how much work they can do…unfortunately, one thing that I would say is with the physicians that are younger. Like 15-17 years ago, I didn't have any physical pain myself…if somebody said they have pain and they cannot work, I was not as sensitive…I would not really identify with them, and I would think they are just trying to get money…if [younger doctors] have pain, it goes only for a few hours of the day; nothing is chronic at that age. Unless you yourself have experienced pain, you would not know what it is.

Surprisingly, CEs' biased heuristics are so strong that they can actually override objective evidence. One such heuristic for three of four CEs was the perception that claimants are "exaggerating" their pain:

> I was just actually dictating last night that somebody I saw yesterday—she did have an MRI of cervical spine that said she had spinal stenosis, she has radiculopathy that was consistent, and she also had back pain, but no MRI of the back was available. So, there was some genuine pain for sure, and it's not that she was making it up, but the *amount* of pain she that she was expressing was completely out of proportion. Like really? She was in so much pain that she would not even flex, extend, or laterally move her neck at all? And then I just touched just to see and she just jerked…she just jumped off the exam table and she could not early on—would not—even lift her leg up...(Dr. E)

Dr. E's comment above demonstrates how, despite conscious understanding of the importance of objective evidence, it is possible for heuristics and CEs' subjective adjudication processes to get in the way of considering objective evidence. CEs use many such attributions about claimants' behavior to determine the credibility of their subjective testimony. Ultimately, claimants' subjective testimony about their illness experience is secondary to the CEs' subjective evaluation of such (or sometimes discounted), as Dr. M says "when I ask them how long they can sit, stand, walk, it just gives me an idea. If I think they could do more, then I put it down on my exam." As all claimants that I interviewed saw CEs, it is interesting to note that claimants were surprised at the amount of their examination that consisted of asking subjective questions rather than a physical examination. It was common for claimants to say that CEs "barely touched" them. A majority of claimants interpreted this as suspicion on the part of CEs—which interviews with CEs points toward the validity of.

Amplifying this problem is the fact that interviewed *CEs report missing medical records 40-60% of the time*, so one major source of objective evidence is missing that much of the time. This statistic stands in contrast with the SSA mandate that "every reasonable effort must be made to obtain from the claimant's medical sources the medical evidence necessary to make a determination of disability"[5], as it is hard to imagine that this is the case 40-60% of the time. Even if claimants remedy this by bring their own records, CEs are suspicious that claimants only bring records that will help their case. Without records, CEs become almost solely reliant on their other trusted indicator—their physical examination—which is pervaded with their individual biases—particularly against those with fibromyalgia.

Discussion

This study provides data and analysis on inconsistency in the evaluation of pain in the DDP from the perspectives of three types of actors in the DDP. The data is presented at four levels of analysis. From the first level of the medical condition itself, the complexity of chronic pain as a component of multimorbid conditions makes adjudication difficult for all studied actors affecting the DDP: medical physicians and institutions, claimants, and CEs.

When claimants enter the DDP, they have widespread chronic pain in multiple parts of their bodies that begins as more localized and becomes widespread. Claimants perceive that physicians' and the SSA's lack of understanding of processes of how "pain spreads to everywhere" leads to dismissal of the pain as "not real" because it is not localized and, in their experiences with physicians, therefore understandable in the biomedical paradigm of specialization. Claimants perceive that their extensive medical history related to such complexity negatively affects acceptance by physicians and the SSA. These views are supported by legal literature, ongoing court cases on the subject, and analysts (including former SSA medical adjudicators) who write guides for applicants for SSDI (Bierman 1998; Masson 1994; Finch 2005; Purvis 2011; Laurence, JD *DisabilitySecrets*; Moore *Social Security Disability Resource Center*).

Interviews with treating physicians and CEs also confirm claimants fears of dismissal. At the level of medical institutions—who are important to the DDP because the evaluation process begins with claimants' treating physicians—claimants see many physicians for diagnosis and treatment of their pain. This "run around" between doctors is due to specialization and

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[5] 20 CFR 404.1512(d) and 416.912(d)

skepticism of pain by physicians, and the mistreatment faced through this process—especially through worker's comp and Kaiser—contributes to worsening of patients' conditions until they are severe enough to warrant SSDI. It is then the resistance of treating physicians to SSDI and systematic non-involvement of medical organizations in helping patients apply for disability that delays the DDP and manifests in insufficient of needed medical evidence for applicants. Of those physicians who were willing to help, claimants noted that physicians did not know what to include on disability forms. Anne Fitzpatrick and Beth Laurence, writers for the legal publication *DisabilitySecrets*, substantiate this data as part of a wider trend for chronic pain patients that treating physicians "commonly do a poor job referencing their patients' levels of pain and inferring what the resulting effects might be on the patients' ability to engage in normal daily activities" (Fitzpatrick *DisabilitySecrets*; Laurence ibid). Additionally, both my data and these secondary sources confirm the need for legal advocacy for these claimants for this reason, as "disability lawyers work with the applicants' doctors to order lab tests, clinical exams, x-rays, etc. to provide the evidence lawyers *know* is needed to win the claims" (Laurence ibid).

Several recommendations come from data on the role of medical institutions. First is to *create standardized questionnaires and evidentiary requirements for treating physicians* for inclusion in the DDP (e.g. physicians' summaries and letters, certain imaging studies). Though *SSR 16-3p* and rulings on specific listings with chronic pain as a symptom provide a range of possible medical evidence to substantiate pain, the inconsistency noted in past literature remains an issue for what evidence is submitted by physicians. Developing such requirements may require SSA advisory committees to clarify specifics on what evidence will be necessary for pain symptoms and listings—especially taking into account that subjective evidence is more vulnerable to *subjective* adjudication in the DDP and therefore needs more clear interpretation procedures than is given in the current rulings. It is hoped that such clarity will improve applications, and also prevent medical institutions and insurance companies from barring certain evidence due to cost—though another consideration for SSA committees may be to exclude high-cost evidentiary requirements.

Second is to focus on *effectively disseminating available resources* for treating physicians and medical organizations on the DDP and their role in it. The SSA does publish guides and an FAQ for treating physicians on the SSA website; however, this study shows that medical professionals do not access these resources. This fact harms claimants, who already have difficulty accessing their physicians and convincing them to help apply for SSDI. At the claimant level—just as with physicians—*effectively disseminating available resources* for applicants must be a focus. Again, the SSA website provides many resources for claimants, but interviewees had trouble accessing and understanding such resources and were unaware of or afraid to seek help at the DDS for fear of employees' influence over their claim. One claimant noticed the well-defined resources available to blind applicants and wished there was similar help for applicants with many overlapping, challenging symptoms. High levels of emotional distress, cognitive impairment resulting from pain, and inability to physically type the forms all prevent effective utilization of such resources. Further research could be conducted, likely through surveys, to *understand the access needs* of this population.

One set of difficult-to-access resources of particular note is on the subject of *using "medical equivalence" of a disability listing* (20 CFR 404.1526 and 416.926). As all interviewed claimants have many conditions, inclusive of pain symptoms not in the listings, claimants had difficulty knowing which of their conditions to list as primary in their application, and as such, establishing medical equivalence of such symptoms to a disability listing is an important resource for these claimants. Physicians are also unaware of medical equivalence, and even if they are informed, they have trouble presenting detailed information on how conditions relate to one another. Accessing and understanding information on medical equivalence to a listing is difficult, and as Loraine Netter of *DisabilitySecrets* notes, "it is rare for a disability applicant without a lawyer to be able to prove that his or her medical condition equals a disability listing", as it is even "difficult to figure out which listing [they] might equal". My data confirms that claimant confusion due to multimorbidity and known denial of chronic pain claims leads to dependence on legal advocates and outside resources that become responsible (in all but one case) for portraying information on listings to the SSA or Administrative Law Judge (ALJ). As one claimant conveyed, the way that she had to craft her disability application for the SSA after being denied was less than truthful, which brought her moral distress. However, the advice she received was correct, and she obtained disability after making recommended changes by her legal advocate.

Interview data from the CE level substantiates that subjective evidence—or indicators *considered* to be subjective by CEs—are clearly subject to biases of CEs. CEs are resistant to diagnoses and tests based on newer models of pain and multimorbidity, like fibromyalgia and the tender point test, because they consider them "controversial" and therefore aligned with being more "subjective". Therefore, as one CE suggests, the advisory committee on the subject must create guidelines and continuing education trainings for staff involved in the DDP on the topic—especially for CEs (see opening quote to this paper). Important in these materials should be notation of known biases used in evaluating pain and other symptoms/conditions and how they do not conform to CE guides and rulings on these conditions.

Resulting from these factors, eleven of twelve claimants had/have over three year waiting periods in the DDP—a problematic inefficiency in the process. During these years, as all claimants were unable to work, claimants have no income, go into debt, file bankruptcy, become homeless, or for those with family/friends, rely on support to not be homeless—though applicants say that this reliance generally strains or destroys these relationships. The damage of long waits extends to their physical and mental conditions due to stress and their decreasing ability to be able to afford treatments. Many applicants acquire mental health conditions—including depression, anxiety, and dissociative disorder—during this period. Therefore, suggestions from claimants include resources for applicants with long wait times to obtain limited income, either through programs like *Ticket-to-Work*, subsidies for employers to hire claimants part-time, or subsidies for claimants.

It is troubling that even though all but one claimant had *multiple* objective indicators of severe chronic pain—including imaging studies and orthopedic surgeries—they were still denied until the ALJ level. SSA-released statistics show that chronic pain conditions have among the *lowest* initial and reconsideration allowance rates but the *highest* reversal rates at ALJ appeals (Meseguer 2013; Laurence *DisabilitySecrets*). Therefore, secondary analysts strongly advise chronic pain claimants that "you will *no doubt* be denied benefits at the initial application state and need to go to a hearing" (Netter *DisabilitySecrets; emphasis added*). Interview data and legal literature show that widespread use of biased heuristics is one important factor for these statistics (Masson 1994; Finch 2005; Purvis 2011). One additional note for further exploration is the relationship of chronic pain denials and gender—since all but one claimant was female—additionally because men are statistically more likely to gain initial allowance for SSDI than women (Meseguer 2013). My data—and statistics of medical diagnoses in general—indicates that women are more likely to be diagnosed with "contested" illnesses like fibromyalgia that have more subjectively-based diagnostic techniques, and that women are more likely to be dismissed by physicians as having psychosomatic illnesses (Hoffman and Tarzian 2001; Werner et al. 2004; Barker 2009). Relatedly, future research should extend to other controversial, subjective-evidence based, complex, and/or emerging conditions like Chronic Fatigue Syndrome, Lyme's Disease, and Somatoform Disorders.

Such high initial denial and reversed appeal rates for chronic pain claims indicates that further research should be done to evaluate the role of other components of the DDP with regard to chronic pain, including medical adjudicators, lawyers, ALJs, and their staff. Though interviewing medical adjudicators was part of my proposal to the SSA for this and future research, my SSA contacts, Laura King and Tom Rush, informed me that these interviews would likely not be approved by the SSA. Regardless of the researcher, this research should be done to obtain a truly holistic understanding of evaluation procedures and denial rates for chronic pain claimants. As this study is limited by a small sample size, more research should be done to obtain a higher level of generalizability for these findings. Nonetheless, the "depth, multiple perspectives, and process" revealed by this study underscores the conceptual payoffs of a small, case study approach, as is utilized in medical and policy research (Morrill and Fine 1997; O'Day and Killeen 2002; Keen and Packwood 1995; Crowe et al 2011).

Policy Recommendations

1. *Establish claimants with chronic pain/complex symptomatology as a category of applicant and evaluate specific needs for this population.* Claimants with multifaceted symptomatology often do not fit into listing categorization and have complex and specific resource needs beyond basic resources easily accessed on the SSA website. User-based design—through focus groups with claimants/advocates and statistical analysis of their application usage—could be used to identify and categorize resource needs for this population and test implementations. *One possible implementation would be to have an interactive online questionnaire prior to the application that provides individually-tailored resources based on applicant responses*. Several specific needs are identified in this study:
    a. *Informational:* Certain procedures in the DDP—like establishing medical equivalence—are needed more by these claimants, who need simple and clear resources on these aspects. One simple change to SSA resources could be bringing medical equivalence procedures more to the forefront of the SSA website.
    b. *Physical and Cognitive Accessibility:* Having multiple physical, cognitive, and psychological ailments render understanding and completing forms especially difficult for the population studied here. Though DDS personnel are available, the perception that these employees have control over application decisions limited claimant usage and increased reliance on outside advocacy. Availability of

resources—both from the SSA and outside advocacy organizations—must be made more accessible and expanded.

   c. *Financial*: As all but two interviewed claimants have over three-year waiting periods in the DDP and go all the way to ALJ appeal, these claimants suffer deteriorating health and extreme poverty. Sustaining financial resources should be made available for those with long waits. Claimants suggested allowances for limited employment/activity (e.g. schooling, *Ticket-to-Work* expansion) that does not affect application outcomes, organizing/subsidizing employers to hire part-time disability applicants, and providing short-term subsidies/loans.

2. *Effectively disseminate available DDP resources directly to treating physicians*. Though the SSA publishes guides and an FAQ for treating physicians on the SSA website, treating physicians from this study do not access these resources. The burden of facilitating physician education cannot fall on claimants, who are confused about the DDP, struggling with severe illness, and often have difficulty getting physicians to participate in the DDP.
3. *Develop standardized evaluation procedures/questionnaires for treating physicians and evidentiary requirements based on symptom/listing*. In the case of chronic pain and other symptoms with underdeveloped/contested medical evidentiary techniques, inconsistent usage/acceptance of medical evidence complicates claim evaluation. Both physicians and adjudicators need clarity and simplicity on what factors must be provided for evaluation.
4. *Develop guidelines for and continuing education trainings on complex symptomatology for DDP personnel*—especially CEs. This recommendation was suggested by a CE. Consideration for clear and simple evaluation as well as noted biases often used in evaluation processes should be part of these trainings (see opening quote by Dr. E for specifics).
5. *Compile and evaluate statistics on how often and why CEs are missing medical records*. Interviewed CEs stated they were missing claimants' medical records 40-60% of the time, which should be confirmed as a larger statistic and evaluated for causal factors.

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