



American Association
for Dental Research

February 15, 2019

Dan O'Brien
Office of Disability Policy
Social Security Administration
6401 Security Boulevard
Baltimore, MD 21235-6401

Re: Docket Number: SSA-2018-0017 – Consideration of Pain in the Disability Determination Process

Dear Mr. O'Brien:

On behalf of the 3,350 individual and 107 institutional members of the American Association for Dental Research (AADR), thank you for the opportunity to submit comments in response to proposed rule, "Consideration of Pain in the Disability Determination Process," (Docket number: SSA-2018-0017).

AADR is home to the Friends of National Institute of Dental and Craniofacial Research (FNIDCR), which includes 32 patient advocacy organizations that represent everything from autoimmune to craniofacial disorders, many for which pain is a significant symptom that affects patients' abilities to work. We are hearing from some patients that in spite of their pain, their conditions are not considered disabilities. For example, members the Ear Community suffer from microtia and atresia or its related syndromes, Goldenhar or cranifacial/hemifacial macrosomia, which are all congenital birth defects resulting in malformation of the ears and/or features of the head and face such as the nose and jaw. Some members of the Ear Community suffer from headaches related to temporomandibular joint disorders (TMJD).

Another experience comes from a writer who is a member the organization HOPE: For Burning Mouth Syndrome. Her career ground to a standstill with the onset of burning mouth syndrome followed by other autoimmune disorders. She is 56-years-old and always expected to work well into her early 70s. However, her health – primarily the pain caused by burning mouth – has changed that vision. She comments that invisible pain is so difficult to manage in any situation, but in the workplace, where one must be on top of ideas, issues, and deadlines, it can be impossible. She has tried countless treatments – traditional (i.e., opioids, gabapentin, etc.), complementary (i.e., physical therapy, acupuncture, meditation), and experimental (i.e., stellate ganglion blocks) – to no avail. She is entering her sixth year of this disorder and has been unable to work full-time since October 2016.

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The Social Security Administration's (SSA's) criteria for disability, on the surface, are a framework by which our health care system can determine who is disabled and potentially prevented from finding employment and needs further assistance. But if we look deeper, we can see that it is also an interdisciplinary nexus for compassionate health professionals, social workers, and patient advocates joining together to empower patients with the medical and social resources they need to flourish. After consulting with research and patient advocate members, AADR provides the following responses to the questions posed in the proposed rule:

Within the United States, which standard scales, questionnaires, or other methods to evaluate the intensity and persistence of pain that are commonly accepted in the medical community do you recommend we consider and why? What information exists about the efficacy or accuracy of those scales, questionnaires, or other methods?

There are several measures that are used by the medical community to assess pain, especially in specialty settings for each of which there is a considerable research base to support their use to assess pain. These include visual analog/numeric scales of pain (Hawker *et al.* 2011), the Graded Chronic Pain Scale (Von Korff *et al.* 1992) and the Brief Pain Inventory (Tan *et al.* 2004). The McGill Pain Questionnaire (Melzack 1975) is an older instrument that has also been used in pain research, but the language found in the test requires a high level of technical expertise.

In general medical/dental practices, questionnaires are not commonly used. Some practitioners may ask patients to rate their pain, but the response scale offered to patients may not be consistent from provider to provider. The information obtained from patients may not be well-documented.

The Graded Chronic Pain Scale and the Brief Pain Inventory assess both pain and disability. The amount of time needed to complete either questionnaire is five minutes or less. Some normative data are available for both questionnaires, depending on the specific pain condition.

To avoid malingering, one option is to train clinical office staff to observe patients and to compare observations among clinical personnel (e.g., how well did the patient walk from the reception area to the examination room? Did the patient exhibit noticeable pain behaviors when rising from a chair? While walking?). There may be a need for training programs that teach these skills and an assessment of the psychometric qualities of such observations. These methods will also have to be protected against the risk of evaluator bias based on factors such as race, gender and insurance status (Lee *et al.* 2016; Wandner *et al.* 2013).

Should we evaluate chronic pain differently than acute pain? If so, why and how?

Chronic primary pain should be listed as its own category of impairments in § 404.1520 app I. The current categories within §404.1520 appendix I include pain as only a qualifier of a medical impairment or, quite clandestinely, as a somatic symptom disorder (see section 12.07). Since many patients with chronic pain, e.g. fibromyalgia, TMJD, chronic regional pain syndrome, do not have diagnoses that qualify under a current category,

they must be classified as pain using the criteria from 404.1529, “how we evaluate symptoms, including pain”. However, we see a problem with these criteria when looking closely at 404.1529(b):

Your symptoms, such as pain, fatigue, shortness of breath, weakness, or nervousness, will not be found to affect your ability to do basic work activities unless medical signs or laboratory findings show that a medically determinable impairment(s) is present. Medical signs and laboratory findings, established by medically acceptable clinical or laboratory diagnostic techniques, must show the existence of a medical impairment(s) which results from anatomical, physiological, or psychological abnormalities and which could reasonably be expected to produce the pain or other symptoms alleged.

The problem with this rhetoric is that chronic pain diagnoses that are not associated with anatomical or physiological abnormalities, like those associated with neuropathic pain, would only have the option for diagnosis by evidence of a “psychological abnormality”. According to Treede, “Pain without any obvious tissue damage was considered ‘psychogenic’ in the 20th century. In the 21st century, we distinguish between nociceptive pain (tissue damage) and neuropathic pain (somatosensory system damage)” (Treede 2018). Thus, if criteria for disability standards are to be up to date with current internationally recognized definitions of pain, they should include a category for primary diagnoses of neuropathic pain that is separate from secondary diagnoses.

Furthermore, Treede *et al.* in association with the International Association for the Study of Pain (IASP) has selected codes for the 11th edition of the international classification of diseases (ICD-11) that classify chronic pain as both a secondary condition of other medical conditions and a primary condition on its own. They define *chronic primary pain syndromes* as follows:

“Chronic primary pain is defined as pain in one or more anatomical regions that persists or recurs for longer than 3 months and is associated with significant emotional distress or functional disability (interference with activities of daily life and participation in social roles) and that cannot be better accounted for by another chronic pain condition” (Treede et al. 2019).

Therefore, by including the ICD-11 chronic primary pain syndromes as their own category in § 404.1520 appendix I, patients functionally disabled by such conditions would not be further disabled by the unjust stigma of psychogenic pain.

If § 404.1520 appendix I contains a new category for chronic primary pain, then its criteria should be formulated and evaluated by a multidisciplinary team, including oral health specialists, knowledgeable of ICF and multimodal treatment of chronic pain. A subcategory of the ICD-11’s chronic primary pain is “chronic primary headache or

orofacial pain” (Nicholas *et al.* 2019). Therefore, section § 404.1529, titled “How we evaluate symptoms, including pain” and section § 404.1616, titled “Medical consultants and psychological consultants” should be expanded to include consultation by oral health specialists experienced with the management of patient’s disabled by orofacial pain. Given the growing awareness of the association between oral health, overall health, and healthy social systems at work, at home, and throughout our communities, oral health and medical professionals should work together to ensure the function, in disability and health, of our country’s workforce.

Should we evaluate nociceptive pain differently than neuropathic pain? If so, why and how? Please submit research or data that support your recommendation.

All pain should be carefully assessed, whether nociceptive or neuropathic. However, the type of pain may be less important than the impact of pain on an individual’s everyday functioning. Multiple studies describe three or more clusters of pain patients (Bäckryd *et al.* 2018). These clusters differ in the degree of psychological distress shown by members of a cluster, their degree of interpersonal/social distress, and pain quality and intensity. Assessing pain alone does not capture these differences, which are in turn tied to health care utilization.

Can health care utilization and treatment regimens employed by physicians to manage patient pain provide objective insights into the intensity and persistence of pain? When should those regimens not be an indication of the severity of an individual's pain?

Health care utilization and treatment regimens should not be used to obtain insights into the intensity and persistence of pain as there are a variety of factors unrelated to pain that affect the level of healthcare utilization. High levels of health care utilization can provide information about a patient’s level of distress, but this should not be taken solely as evidence of pain. Health care utilization may also reflect the provider’s perceived ability to treat the patient’s pain. In other words, if a provider feels unable to treat the pain, it may result in a low level of health care utilization even though the patient is experiencing intense and persistent pain. The level of health care utilization may also be indicative of economic resources and social support, i.e. having family, friends or other caretakers to take them to a facility, and not the patient’s pain intensity or persistence.

Is there any additional information that we should consider when we evaluate pain in our disability program?

Yes, a person’s level of pain and disability and their medical utilization is greatly influenced by his/her level of psychosocial, interpersonal and emotional distress. Both pain and distress need to be assessed and treated.

§ 404.1520 appendix I, section 12.00D titled, “How do we consider psychosocial supports, structured settings, living arrangements, and treatment” and § 404.1529(section (C)(4)) titled, “how we determine the extent to which symptoms, such as pain, affect your capacity to perform basic work activities” should be expanded and aligned with

the language of the ICD-11 functioning properties of chronic pain and the International Classification of Functionality, Disability and Health (ICF). In 2001, the ICF was developed by the World Health Organization (WHO) as an “international, scientific tool for the paradigm shift from the purely medical model to an integrated biopsychosocial model of human functioning and disability” (Towards a common language for functioning, disability and health: ICF 2002). The ICF, by classifying impairments from the ICD-11 as disabling or functional in relationship to the environment, provides a conceptual framework and shared language that the SSA and healthcare system can use to synergize medical and social interventions. Nugraha *et al.*, in association with the IASP, established a consensus to determine which of the ICF’s codes for *activity* and *participation* should have matching language as *functional properties* for the ICD-11’s classification of chronic pain (Nugraha *et al.* 2019).

Furthermore, by introducing these ICD-11 functional properties for chronic pain and ICF into § 404.1520 appendix I and § 404.1529, health professionals will have a suitable foundation to promote behavioral and lifestyle interventions, e.g. nutrition, exercise, positive psychology, that are adjuncts to pain management in association with prevention, treatment, or reversal, of our country’s most prevalent chronic diseases (Cristina de Oliveira *et al.* 2017; Gäbler *et al.* 2018; Hayes and Hodson 2011; Hayes *et al.* 2012; Peters and Lautenbacher 2018; Tick 2015).

Once again, we are grateful for the opportunity to comment on this proposed rule. We hope that this effort to update the current regulations and bring them in line with current scientific understanding of pain will result in more inclusivity of the patients in our community. Please do not hesitate to reach out to Dr. Seun Ajiboye, Director of Science Policy and Government Affairs at sajiboye@iadr.org.

Sincerely,



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