Fibromyalgia and Chronic Pain in Academic and Professional Settings

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Fibromyalgia can be defined as "a syndrome characterized by chronic widespread pain, joint stiffness, sleep disruption, and other systemic symptoms, including mood disorders, fatigue, and cognitive dysfunction." (Chen, Carpenter, Flaherty, 2019) "People with fibromyalgia likely have sleep disorders; severe changes in mood and thinking, depression and chronic anxiety; headaches; impaired memory; irritable bowel syndrome (IBS); multiple chemical sensitivity (MCS); restless legs, skin and temperature sensitivity; and tingling" (*Job Accommodations Network*, 2022) What are the impacts of fibromyalgia? How can we be more accommodating of people with fibromyalgia, chronic pain and other disabilities in academic and professional environments?

Women are more likely to be diagnosed with fibromyalgia than men, and data suggests women are more likely than men to have multiple disabling conditions. (Goodwin, Morgan, 2012) Women with fibromyalgia, reported feeling "guilt and frustration for not being able to continue to fulfill gender expectations related to housework, family life, and marital relationships." (Dépelteau, Lagueux, Pagé, Hudon, 2021) So, in addition to occupational and academic experiences, women communicated feeling an added pressure to perform more tasks in their domestic lives than men.

Historically people with disabilities were excluded from opportunities to succeed in academic and professional settings. A vital turning point in the history of disability justice, is *The Americans with Disabilities Act, (ADA)* initially enacted in 1990. Under the *ADA*, you have a disability if you have a physical or mental impairment that substantially limits a major life activity. (*Job Accommodation Network*, 2022) This grants you the right to reasonable accommodations at work and school. However, the responsibility to request accommodations still rests with the employee. (Chen, Carpenter, Flaherty, 2019) Those in leadership positions

often fail to create safe spaces where accommodations are adequately implemented. This means that accessibility is commonly limited, and many disabled people fear disclosing their condition due to stigmatization, skepticism, and ableism.

The expectation that disabled people must take on the role of self advocacy is burdensome when those in power are often unwilling to take them seriously, "institutions have a responsibility to promote awareness and understanding of accommodation policies" (Goodwin, Morgan, 2012) Leaders need to educate themselves on "allocation of suitable accommodations, hiring and retention of individuals with disabilities, disability awareness training for employees, human resources personnel who are familiar with disability and accommodations, and a fair system for submitting grievances" (Chen, Carpenter, Flaherty, 2019) It is integral that "Individuals with chronic health conditions who seek work accommodations need supportive and informational services to navigate the process." (Chen, Carpenter, Flaherty, 2019)

People with fibromyalgia "report a lot of negative feelings, often naming frustration, shame, the perception of being useless, and guilt." (Dépelteau, Lagueux, Pagé, Hudon, 2021) however, "these feelings were most often related to the inability to take part in daily activities, and to the social environment's lack of understanding." (Dépelteau, Lagueux, Pagé, Hudon, 2021) This perspective is an example of the 'Medical Model' versus the 'Social Model' of disability. "In the Medical Model of disability, a person's limitations are seen as the primary cause for disability, and a cure as the solution. The Social Model shifts the focus from the individual to the society that excludes them, making a critical distinction." (Chen, Carpenter, Flaherty, 2019) These models of disability are important to acknowledge, because the experience of disability is often difficult due to stigmatization and ableism, rather than solely the condition itself.

Accommodations make a world of difference, and the Job Accommodation Network (askjan), a service of the U.S. Department of Labor's Office of Disability Employment Policy, is an incredible resource to learn more about specific accommodations available for fibromyalgia. Unfortunately, many people with disabilities are unaware of their rights and options, and it should be more accessible to ask for accessibility. "[Leaders] could ensure that individuals receive information about accommodations and how to request them during the onboarding process, and distribute this information periodically, so [everyone] is aware of their rights and seek help if needed" (Chen, Carpenter, Flaherty, 2019) Disclosing your condition is something that often feels personal and vulnerable, normalizing discussions about accommodations make it easier for everyone to thrive in their academic and professional settings. People with fibromyalgia and other disabilities are valuable parts of our teams of colleagues and peers, and can be very successful, with the ability to adapt to better manage their symptoms.

Positive change is both necessary and attainable. We all need to take a role in learning about disabilities and how to make spaces more accessible to everyone. When someone discloses their condition, be understanding, believe them, value their achievements and include them like you would anyone else. "Workplace climate and perceived support of colleagues and supervisors play an important role in disclosure." (Chen, Carpenter, Flaherty, 2019) This means that cultivating a supportive professional climate can empower people with disabilities to feel safe to disclose their situation and ask for help. "Our obligation to support colleagues who have chronic illnesses goes beyond an ethical responsibility and includes a legal responsibility to ensure an equitable workplace" (Goodwin, Morgan, 2012) Exercising this obligation will lead to crucial advancement in society.

Sources

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