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The Impact of Pain on Work and Professional Careers

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Pain is the second commonest reason given for absence from work with an annual loss in the UK of 30.8 million working days (Office for National Statistics 2019); it costs the US \$635 billion in lost productivity and medical bills (£470 billion) per year (Esquibel and Borkan 2014); for Sweden it is SEK 87.5 billion (£7.37 billion); and for Australia lost productivity costs AUS\$1.4 billion (£0.77 billion) (Phillips 2009). According to the World Health Organization (WHO 2018), musculoskeletal conditions are the second largest contributor to disability worldwide, with the greatest proportion of persistent pain accounted for by musculoskeletal conditions. In addition, the Global Burden of Disease 2016 survey (GBD 2017) highlights the significant disability burden associated with these conditions, being the second highest contributor to global disability. The prevalence of musculoskeletal conditions varies by age and diagnosis, with 20-33 per cent of people across the globe living with a painful musculoskeletal condition. Chronic widespread pain (CWP) is defined as musculoskeletal pain in multiple locations that represents generalized body pain (Okifuji and Hare 2014) and is one of the three most common reasons for long-term illness and disability (Löfgren et al.

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2016). In some individuals these pain symptoms persist indefinitely and develop into a chronic condition (i.e., pain lasting over three months or continuing beyond the duration of expected healing), for which the emphasis is on managing the condition, as opposed to curative measures, for example, Fibromyalgia, rheumatoid arthritis and Parkinson's disease (Magrinelli et al. 2013).

The relationship between the physical, psychological and psychosocial elements of pain is extremely complex, with individual differences playing a crucial part in pain perception and disability (Boersma et al. 2014; Casey et al. 2008). Elements such as negative pain beliefs, pain chronicity, depression, learned helplessness, cognitive distortion and pessimistic beliefs about the future interact to create a state of pain and disability. Chronic musculoskeletal pain, a subset of CWP is known as Fibromyalgia Syndrome (FM). FM is characterized by hyperalgesia (i.e., an increased sensitivity to pain [Okifuji and Hare 2014]); it is a chronic, frequently debilitating illness for which there are no definitively curative treatments, although most generally used approaches focus on an individual's psychological and psychosocial functioning, as well as physical components (Nielson and Jensen 2004). Although technically separate conditions, CWP and FM can be treated as overlapping entities (Okifuji and Hare 2014), consequently we have used case studies of individuals with FM to demonstrate how pain interacts on individual's experiences of work and disability. Interestingly, 80 per cent of those diagnosed with FM are women, thus our case studies are based on the experiences of women (Löfgren et al. 2016; Weir et al. 2006). In order to explore the impact of CWP and FM on experiences of work and disability, this chapter focuses on the mechanisms of these impairments, how they are measured and treated, and how they impact on disability and work.

Fibromyalgia is useful as an exemplar as it is frequently reported to be characterized by women from lower socioeconomic backgrounds, exhibiting behavioural problems (Löfgren et al. 2016). There appears to be a paucity of research that has looked at an educated, skilled population from higher socioeconomic backgrounds, consequently we present two case studies to highlight the differences in the experiences of two professional women (one managerial and one business owner) suffering from FM, relating those experiences to the understanding, measurement and treatment of FM, and the impact that their experiences has had on their ability to work, as well as the consideration of how clinicians and organizations can assist employees with CWP and FM.

Mechanisms of CWP and FM

Pain evolved as a survival mechanism warning of tissue damage and is a combination of external stimuli and pre-existing patterns in our brains built up from previous experience (Cohen and Mao 2014). The IASP (International Association for the Study of Pain) definition of [human] pain is 'an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage'. The transmission of a stimulus to our perception is a series of transmissions from one nerve to the next via synapses, each of which provides an opportunity to modify the transmission (Stucky et al. 2001). In the past, prior to the gate theory (i.e., a mechanism that exists within the dorsal horn of the spinal cord, the connections within which determine when painful stimuli go to the brain) (Melzack and Wall 1965), it was believed that the experience of pain was proportional to the strength of the afferent (incoming) peripheral nociceptive drive in the area perceived to be painful (Harper et al. 2016). However, the perception of pain does not function in this manner, with some individuals experiencing intense pain with no nociceptive stimulation and others with serious injuries reporting minimal pain. The placebo effect demonstrates this phenomenon very graphically. One of the reasons for this is Neuronal Plasticity (NP), which is a term used to refer to rapid or longer term changes in the nervous system (Cramer et al. 2011). Changes in neuronal structure; connections between neurons; and alterations in the quantity and properties of neurotransmitters, receptors and ion channels result in changed functional activity of neurons in the pain pathway. NP can modify the pain inhibitory systems, resulting ultimately in decreased or increased pain. Injury, inflammation and disease can all induce neuronal plasticity and increase pain by means of increased excitatory or decreased inhibitory mechanisms (Stucky et al. 2001). Like memory (the processing of which has similarities to the processing of pain), there are differences in immediate, medium and long-term effects of a painful stimulus, and the ability of the central nervous system to modulate pain signals applies not just to the moment of initiation of pain, it also allows change in pain perception with time. The phenomenon of temporal summation can process an innocuous stimulus to become painful when invoked repetitively. NP can result in short-term changes that last minutes to hours, or long-term changes which may become permanent. Even transient stimuli can induce gene expression in the cell body of the neuron that causes new receptors to form and change the structure of the cell and thus its longer term function. Consequently,

there is no known chronic pain condition where the observed extent of peripheral damage engenders a consistent level of pain across individuals (Harper et al. 2016).

In the case of FM, changes in the central nervous system (CNS) of the spinal cord and brain can thus manifest themselves as being structural, functional or metabolic, resulting in a chronic pain syndrome, characterized by widespread muscle pain, tenderness and fatigue (Löfgren et al. 2016). Common symptoms also include: disturbed sleep, cognitive problems, bowel and bladder dysfunction, decreased muscle endurance, mood disturbances, memory problems, vocabulary deficits and anxiety (Dick et al. 2008). The pathophysiological nature of FM is multifactorial and there have been a number of explanations of what occurs in those suffering from FM, for example, a deficient regulation of blood flow in muscle during physical activity (Gerdle et al. 2010), a disturbed function of the central nervous system (Cohen and Mao 2014) and an impaired inhibition of pain (Linder et al. 2014). Depression is often seen as comorbid with FM which is associated with dysregulated inflammation in the CNS (Burke et al. 2015), with a rate of 22 per cent compared to 7 per cent of the general population, and is inversely related to work capacity (Linder et al. 2014). In addition, over and above the effects of depression, FM sufferers can experience: pain-related anxiety; 'fear of pain' and assoavoidance of movement that causes pain (fear-avoidance); catastrophizing (i.e., an exaggerated negative mindset brought to bear during actual or anticipated painful experience) (Sullivan 2009; Westman et al. 2011). These cognitive disrupters play a key role in the pathophysiology of chronic pain, shaping individual differences in both the experience of FM and treatment outcomes (Lee et al. 2018). It is not surprising, given the psychological stress that FM sufferers are under, that they report significantly reduced quality of life and an increased inability to work, with research clearly demonstrating a clear relationship between pain and the other symptoms of FM (e.g., Sullivan et al. 2013).

As CWP can only be really understood from the perspective of the individual, the following case studies explore the experiences of two FM sufferers from two different perspectives. Case Study 1 documents the relationship between Lindsay's declining health, her career and ultimately her ability to work. In contrast, Case Study 2 looks at how Helen has been able to return to her working life since she has received a diagnosis and appropriate medical interventions.

Case Study 1: Lindsay

A 55-year-old woman who suffers debilitating pain and exhaustion due to Fibromyalgia, Crohn's Disease, Irritable Bowel Syndrome, Diabetes, as well as arthritis in her hands and feet. In addition, her medication is restricted due to reactions to morphine-based drugs. She began working in the UK National Health Service (NHS) as a receptionist, progressing via staff training and deputy manager, to the post of practice manager which she held for nine years, although, due to poor employment practices and the need for flexibility, she is now working again as a receptionist. Her previous employment, working for a General Practitioner (GP) practice as Practice Manager, ended badly when, after a period of four weeks ill health, she was accused of working three to four hours below those she was contracted for. Yet when she analysed the sign-in logs she was actually working at least three hours over her contract hours each week and was not paid overtime even when called in on weekends. ACAS (Advisory, Conciliation and Arbitration Service) advised her that they were in fact in breach of contract. had unlawfully deducted wages, which cumulated in constructive dismissal. She had a strong case to take the employer to an Industrial Tribunal but, due to high levels of fatigue and constant pain, could not face going through such a demanding process. Consequently, all she received was the deducted wages.

Lindsay is adversely affected by work pressures, as she does not have the physical reserves to work in the same way as other employees. She has great difficulty climbing stairs, sitting down for more than 20–30 minutes, is limited in how far she walks and is constantly tired and in pain. In a morning she has to get up two hours before she leaves for work in order for her pain medication to take effect and for her to get washed and dressed. As with her previous employer, no attempts have been made by her current employer to investigate the possibility of reasonable adjustments, rather they have pushed her to do things which are detrimental to her well-being. For example, on explaining that she was having substantial difficulty having to repeatedly carry trays full of work and could no longer continue, her manager told her to take a short break and get back to it.

She began in the role of Office Manager at her current employer but after only a few months was told that she was not doing the job and they would not pay her as such. In fact, she could not perform her job because answering the phones to patients took priority and, with a receptionist down, it took most of her time. This was compounded as the impact of pain on her concentration levels made it difficult for her to shift from task to task easily. Consequently, she was offered the post of receptionist at another surgery owned by the same directors, at a reduced rate of pay and no formal contract. Also, when it came to allocating bonuses she received 50 per cent of that received by other staff. It seems that these employers are also guilty of constructive dismissal, discrimination on the grounds of ableism, exploitation and generally poor employment practice.

Lindsay reflects that she has never had any advice or support at work and they do not even accept that she falls within the disability category protected by the Equality Act 2010. Neither employer gave any concessions because of the pain and, in her current job, she has to make up any hours she needs to take off work to attend hospital or clinical appointments. She suffers from bouts of depression, questioning the point of it all. Her sleep is very disturbed by leg and arm pain. Lindsay is very concerned about the effect all of this is going to have on her pension, especially as her previous employer failed to pay the correct pension contributions. Her distress is increased as she works for GPs, who ought to have a grasp of the ramifications of pain on an individual's working life. She feels that that people do not understand the impact of pain on physical and psychological health and how debilitating it is, writing it off as something that people can control.

Case Study 2: Helen

A 60-year-old owner of a hair salon, Helen has suffered from many debilitating issues for the last 20 years, and it is only recently that she has received a diagnosis of Fibromyalgia and pain medication. Over the last ten years her condition began to deteriorate but she was determined to keep on working. However, as the pain increased she was able to do less and less. As she owns the business she was able to make all the necessary accommodations but believes if she had worked for someone else she would have been out of work several years ago.

She had visited the doctors many times and was told that the problem was her weight, so they put her on water tablets to remove the build-up of fluid in her legs. The pain kept on getting worse and the times she could work became more and more unpredictable. Her best friend told her not to be so lazy, and no one understood because they could not see anything wrong with her. She started to fall asleep whenever she sat down, and her physiotherapist admitted that there was nothing more she could do for her. She got the point when she could no longer continue and told her doctor that she 'could not take any more'. Her doctor said that he would 'mend [her]' and 'put [her] back together'; however, when he did not make any progress he 'sacked me off'. She went to see yet another doctor who finally began the process of diagnosis. Helen feels that she has had to fight for everything and that she has had no real help until recently. She was told by a woman from the benefit service that Fibromyalgia is a benefit dodge because you cannot see it, and anyone can say they have it. She still went into the salon everyday but said she "felt like a spare part, like my life was over"; she had become unable to stand, could not cut hair, had given up driving and was reliant on a mobility scooter to get around.

Helen says that now she has a diagnosis and is receiving treatment, she feels like 'I have my life back' and says that this is just the beginning of the treatment. She said it was the support that kept her going, and was sure that if she had not had the support of her co-workers and customers, she would not be here now (i.e., she would have committed suicide), although her relationships have changed. Helen now goes to bed at 7 pm and has had to cancel many social engagements simply because she was not physically able to undertake them. Her best friend gets angry at her for not being able to do the things she did before; however, Helen is an optimist and is sure that she will get her life back.

Measuring and Treating CWP and FM

Pain assessment is a critical prerequisite for pain diagnosis and classification to guide clinicians to determine which treatments may be effective, with the focus on the restoration of function, including health and work ability (Fillingim et al. 2016). Since pain is inherently a subjective sensation, evaluation is also subjective, and the measures in use have significant limitations with no gold standard objective measure of pain at present. Visual analogue scores (VAS) are not linear, so a pain score of six does not mean that the pain

is twice as bad as three, anymore than 'F' is twice as much as 'C' (Klimek et al. 2017). Nevertheless it is accepted that they are treated mathematically, even though in reality they are rank order rating scales. At present the evaluation of pain has much more in common with psychology than that of biochemistry, with the use of psychometric scales, such as VAS, to document subjectively perceived symptoms. Clinicians and researchers must rely on the patient's self-report of pain severity. As such, the identification of objective markers that could simultaneously validate chronic pain symptoms and be used in elucidating underlying pathologic processes would be of significant benefit (Napadow et al. 2010). This mechanistic variability has made the development of effective clinical interventions and therapies difficult, and it is increasingly recognized that in order to effectively treat pain the individual needs to be treated from their own mechanistic standpoint (Wieckiewicz et al. 2015). For example, in peripheral nociceptive pain such as trauma or surgery, the pain goes away when the nociceptive afferents are no longer stimulated, making treatments such as opioids or anti-inflammatories very successful (Harper et al. 2016). In peripheral neuropathic pain (e.g., neuralgia or diabetic neuropathic pain), the primary nociceptive afferents are damaged or dysfunctional and only respond to some drugs. Pain may resolve with healing or in some cases the pain becomes permanent. Treatment using centrally acting drugs achieves a satisfactory response in no more than 30-50 per cent of individuals (Magrinelli et al. 2013), with non-pharmacological treatments (e.g., physical exercise and cognitive behavioural therapy) also having some evidence for their success. Similarly, interventional medical treatments can be used but are not uniformly successful. This further supports the belief that an eclectic approach can achieve only limited results and only a highly specific approach to the individual's experiences can be effective.

There is increasing emphasis on the relationship between pain and psychosocial processes, especially in relation to chronic musculoskeletal pain and disability (Boersma et al. 2014), with it being claimed that psychosocial factors are proven predictors of chronic pain and disability in the acute and subacute stages of pain: arguably this has limited application in practice. These factors include emotional factors (e.g., stress, anxiety and depressed mood), cognitive factors (e.g., beliefs, expectations and catastrophic interpretations) and behavioural factors (e.g., avoidance, coping strategies and passivity): those individuals with the highest risk factors show the highest levels of pain. However, they do not distinguish between individuals whose pain results from an injury as opposed to those who acquire the condition through the course of life. Neuropathic pain can be evaluated using scales such as Leeds Assessment of Neuropathic Symptoms and Signs (LANSS) (Bennett 2001)

and quantitative sensory testing (QST). For FM there is the Fibromyalgia Severity (FS) score, which is a combination of the Widespread Pain Index (WPI) (i.e., a count of 18 painful sites) and the Symptom Severity (SS) scale (Wolfe et al. 2016). In the FM research there appear to be crucial differences in how the antecedents of FM are viewed. Some research has taken the approach that psychosocial and socioeconomic factors, fatigue and sleep, workplace stress and behaviour problems are predictors of FM (Wolfe et al. 2011), whereas others take the view that these are outcomes of FM which are useful in the diagnosis and treatment of FM but are not a cause of FM (e.g., Dick et al. 2008; Wideman and Sullivan 2011). In addition, while it is claimed that measures such as FS, WPI and SS are objective, they use discrete variables (WPI—ves/no) and four-item rating scales (SS—no problem/severe problem) in order to produce a scale total. As the WPI scale does not allocate a measure of pain experienced by the individual in the region specified and the SS does not cover the key symptoms of FM (see Wolfe et al. 2011 for an argument against this inclusion), the resulting total cannot fully reflect the experiences of FM sufferers. For example, if on a person's personal 1–10 scale of pain they initially experience pain of 6–7 but if this is experienced on a daily basis this then becomes 'normal' and what they measure all future pain against. This can and does fluctuate dependent on a number of physiological, psychological and sociological factors.

Although the above measures are widely used, especially the WPI and the SS, they are all based on self-report and as such are highly subjective: they are as much a reflection of the clinician's ability to administer the measure as they are of the pain suffered by the patient. A recent self-report scale developed by Cook et al. (2013), the Pain Behaviors Self-Report, uses 'behaviours that typically indicate to others that an individual is experiencing pain'. It includes non-verbal displays, sighing, crying, guarding and facial expressions, as well as verbal reports. As opposed to pain itself, pain behaviours are observable and quantifiable, and they can communicate the pain being experienced to others and are often effective in eliciting support from others. It is easier for individuals with chronic pain to recall their behaviours than it is for them to provide an assessment of their pain levels, especially as the way in which individuals describe pain varies depending on age, gender, condition and race (Jensen et al. 2013; Stotts et al. 2007).

Once diagnosed there is a range of treatments available to sufferers of CWP and FM, including pharmacological, physical and psychological, which vary between and within countries (Bicket and Cohen 2018; MacFarlane et al. 2017; Magrinelli et al. 2013). Lindsay was fortunate to get an early diagnosis, but it took Helen years, going between clinicians to finally get a diagnosis.

Helen's case study clearly highlights the relationship between her lack of clinical diagnosis and her quality of life and ability to work, all resulting from a lack of appropriate treatment. It is crucial that individuals are involved in the decisions around their treatment, which strengthens their own resources and can reduce stress through increased self-efficacy (i.e., a person's belief that they can achieve the goals they set themselves) (Glavare et al. 2012; Jones 2016). For some, like Helen, drug interventions worked extremely well, whereas for Lindsay they provided limited efficacy. The benefit of being involved in all aspects of their treatment is possibly even stronger for professionals, such as Helen and Lindsay, who have higher levels of internal locus of control and self-efficacy (Broadbridge and Fielden 2015).

Work, Disability, CWP and FM

Work is a key factor in the physical and psychological well-being of individuals, as well as being an important source of social support, especially for women, and the loss of work through disability can lead to feelings of loneliness, social isolation and economic hardship (Löfgren et al. 2016). Close personal relationships can be placed under greater strain as a result of job loss and if these relationships fail to provide the expected level of support, individuals may withdraw from the relationships (Fielden and Davidson 1999). As Helen pointed out, because there are no visible signs of Fibromyalgia, family and friends can be not just unsupportive but actually uncaring and hurtful. Close relationships that do not survive the impact of a disability through pain will not just deprive individuals of an important source of social support but become an additional source of stress and a potential loss of those who act as carers. This has been found to be particularly deleterious for managers and professionals (Fielden and Davidson 1999), although they are more likely to have an elevated source of self-efficacy, which enables them to adjust better to their situation and reduces the chance of them engaging in inappropriate coping mechanisms, such as fear of movement (Jackson et al. 2014). Work is also significantly related to depression, developing positive coping strategies, higher activity levels and diverting attention, and protecting individual's mental health (Tan et al. 2001).

The more effective an individual's coping strategies the more likely they will be able to retain at least some level of paid employment, although not at full capacity (Beaton et al. 2005). It is claimed that this is particularly relevant to musculoskeletal disorders, as can be seen from Lindsay's experiences, although maintaining some level of work is contingent not only on the individual but

on the workplace proving necessary adjustment, receiving a prompt diagnosis and effective treatment. This can be monitored with questionnaires, such as the Work Limitations Questionnaire (WLQ), which assist employers in developing a more objective picture of the individual's capacity for different elements of work (Beaton et al. 2005).

Chronic pain represents a significant indirect cost to employers in terms of lost productivity; although many people continue to work with chronic pain, the focus is on work-related absences (van Leeuwen et al. 2006). Interestingly, there is no shortage of literature looking at the relationship between disabilities from musculoskeletal conditions and how to assist individuals to get off benefits and back to work (for a comprehensive review, see Escorpizo et al. 2015). It is perhaps no wonder that Helen's doctor viewed patients claiming to have Fibromyalgia as benefit dodgers, although there are guidelines set out by the NHS about who can diagnose Fibromyalgia and the criteria for doing so. In addition, there is minimal evidence to support the effectiveness of the rehabilitation programmes on offer, except those which focus on the individual and their specific needs (Löfgren et al. 2016; Suoyrjö et al. 2009). Rehabilitation programmes that involve the individual in every aspect of decision making and support them in their return to work increased the individual's coping ability, with women with chronic pain benefiting more from such an approach than men (Jensen et al. 2005). Lindsay's case study highlights the poor outcomes that occur when individuals do not have access to rehabilitation programmes and/or their organization fails to make accommodations within the working environment that would alleviate the barriers faced by those with chronic pain.

Conclusion

It is really important to recognize that the relationship between the stimulus and the consequence of chronic pain is not deterministic and is extremely variable and the International Association for the Study of Pain's (2019) definition of pain does not tie the experience of pain to the stimulus, considering pain and suffering to be separate matters. The measurement or evaluation of pain is essentially subjective and there is no measure better than a subjective report. The impact of individuals suffering from chronic pain on work performance is related to the level of pain experienced, with higher levels of pain strongly related to disability and the inability to work (Okifuji and Hare 2014). One of the key issues for both Helen and Lindsay was receiving a diagnosis, yet the way in which WCP such as FM is measured is highly subjective

and completely reliant on self-report from the individual. What do questions such as on a scale of 1–10 how would you rate your pain accomplish? The answer is relative to what pain an individual has experienced previously and as that is unknown it is simply an abstract concept. Although it is not possible currently to measure pain directly, behaviours that demonstrate if an individual is experiencing pain can be objective, for example, the Pain Behaviors Self-Report (Cook et al. 2013). This tends to provide clinicians with a much more accurate assessment of an individual's condition than more traditional methods (Dixon et al. 2007).

The perception that you cannot easily measure FM appears to lead to the assumption that those from lower socioeconomic backgrounds often 'claim' to be suffering Fibromyalgia, with the assumption being that they are doing so to get out of work and enter the benefit system. Studies rarely consider more than the age and gender of their sample, with characteristics such as education, salary and occupational status generally absent. The lack of this differentiation makes the identification of individual's socioeconomic level impossible, yet this can be a significant factor in work motivation and the ability to cope with the stress resulting from dealing with a disability in the workplace (Jackson et al. 2014). In addition, those in more professional or managerial positions often have greater flexibility and control over their working patterns and working locations. Those from higher socioeconomic groups are likely to be able to afford different approaches to rehabilitation, as Helen commented, if she had not had the flexibility and control over her work-place accommodations, she would not have been able to carry on work as long, or return to work as quickly. Conversely, in cases such as Lindsay's, where such flexibility is denied (often in breach of the Equality Act 2010), it makes it difficult for those with chronic pain to maintain the same level of productivity: they end up having to reduce their hours and occupational position just in order to remain in work.

The support individuals receive from their work colleagues is essential for those with chronic pain to cope effectively on the job which can be difficult when the effects of pain are variable. Those who are faced with little organizational support have to cope with excessive job demands, may feel dominated, abandoned and excluded (Glavare et al. 2012). In some instances where organizations are supportive and provide suitable accommodations, the individual with the disability can face backlash from colleagues who may feel that the individual is receiving the same remuneration but for less productivity (Löfgren et al. 2016). Negative responses from co-workers can include exclusion, not being listened to or being respected and can even lead to the individual being bullied or harassed (Woolnough et al. 2020; Glavare et al. 2012).

The relationship between psychosocial stressors and the development of depression in susceptible individuals, such as those with chronic pain, is well documented (Pittenger and Duman 2008). Thus, organizations who allow such behaviour are directly responsible for the deterioration in their employee's physical and mental well-being. However, as Lindsay reflected, even though she had a case against her employer, she did not have the physical or mental reserves to pursue litigation.

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