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Valued Living and Fibromyalgia

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Valued Living and Fibromyalgia

by

Sean Elizabeth Edwards

A doctoral research project submitted to the School of Psychology of
Florida Institute of Technology
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Abstract

Valued Living and Fibromyalgia

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Prior research has attempted to identify links between trauma and chronic illness, specifically, Fibromyalgia (FM). Due to the lack of understanding of the etiology of FM and the high reports of trauma and stress and FM, many have theorized there is a connection. There is minimal literature on an individual's perception of their FM and their willingness to engage in value based behavior. The idea of value based behavior is founded on Acceptance and Commitment Therapy and the mindfulness strategies meant to increase psychological flexibility and living a life according to one's values. The current research evaluated patients with FM and their perceptions of their illness, stress, psychological factors and ability and willingness to engage in values. Moreover, the current study discussed the correlations between the aforementioned factors and how FM impacts them, as well. It was hypothesized that those who experience more significant symptoms of FM will have less acceptance of their pain, experience higher levels of perceived stress and more significant psychological symptoms. Depression, stress, and FM impact were all possibility correlated, supporting the hypothesis that symptoms and functional impact of FM were associated with higher levels of depressions and stress. This is consistent with the literature and supports the need for psychological intervention for individuals suffering the chronic and debilitating disease of FM. However, there was no relationship between FM impact scores and valued living in the last month.

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Fibromyalgia

Fibromyalgia (FM) is defined as an autoimmune disease that affects the central nervous system and has shown to cause dysregulation of the endocrine and sympathetic nervous systems (Lumley et al., 2008; Yavne et al., 2018).

Fibromyalgia affects approximately 4% of the population and of that percentage, most are women (Lumley et al., 2008). Fibromyalgia is characterized by ongoing and widespread muscular and neuropathic pain, tender joints, fatigue, sleep disturbance, and mood disorders (Lumley et al., 2008; Sabik, 2010). In addition to the physical symptoms, individuals diagnosed with fibromyalgia also suffer cognitive difficulties that are frequently referred to as “fibrofog” in the clinical community. This is a term used to describe cognitive difficulties fibromyalgia patients suffer due to their widespread pain and frequent sleep problems (Yavne et al., 2018). Together, these symptoms frequently lead to a number of life changes, including limited functioning in daily life. The disease and its associated emotional impacts can result in FM patients having difficulty finding the ability to engage in medical and psychological health care leading to a poorer sense of overall well-being. This project assessed physical and psychological factors that interfered with daily functioning. We will also assess the relationship of these factors to a measure assessing patient’s value related behavior.

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Fibromyalgia: Etiology and Symptomology

FM has been researched in both the medical and psychological communities; however, a number of questions remain. FM is believed to be associated with or triggered by some sort of trauma, illness, infection or injury (Sabik, 2010). While there is still controversy surrounding the etiology of fibromyalgia, it is thought to be a biopsychosocial disorder that arises from multiple underlying causes (Affleck et al., 2001). FM is associated with muscle pain and specific tender points and can be categorized as a rheumatic disorder. Rheumatic disorders are described as any disease that impacts the joints, tendons, ligaments, bones and muscles (organs can be affected as well) (National Institute of Arthritis and Musculoskeletal and Skin Diseases). It is the second most common rheumatic disorder and is associated with comorbid diagnoses of other kinds such as chronic fatigue, irritable bowel syndrome, chronic headaches, other chronic pain conditions and mood disorders including depression, and anxiety (Clauw, 2014).

There have been a number of difficulties in the definition and diagnosis of this disorder. Moreover, even as there are advances in the study of FM, some medical providers continue to question the existence of the disorder. Previous diagnostic criteria for FM made it a diagnosis of exclusion. That is, other factors or possible disorders had to be ruled out before the diagnosis could be made (Sabik, 2010). This meant that patients had to be tested for a myriad of other disorders

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while continuing to suffer joint pain and unexplained symptoms. Patients who have been diagnosed with FM have usually gone through many doctor visits, including various specialists. Generally, they have had to advocate for themselves to be diagnosed with the disorder. This adds to the stress associated with an already life-altering disease. Frequently when an individual has been experiencing life changing symptoms and spent significant amounts of time searching for answers and subsequently get a diagnosis, they are relieved – there is finally an answer. This is not usually the case with FM, as it has no cure and is frequently a lifelong disease. Individuals who are finally diagnosed with FM have to adjust to life with this chronic illness that does not have a specific treatment identified. Additionally, patients with FM are frequently labeled as somaticizers, “dramatic”, or exaggerating minimal concerns. They are doubted and the disbelief from everyone around them creates a negative self-perception. The difficulty in diagnosis and treatment can lead to discomfort and distrust of the medical community. Moreover, they may feel alienated from loved ones in that their disease is often questioned by family and friends. (Sabik, 2010).

Physiology & Development of Fibromyalgia

As noted, the specific etiology of FM has yet to be determined. Much of the dispute around FM is in regard to physiological and psychological factors. FM is

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known as a diagnosis that is impacted by stress, so some in the medical field assume it is a somatization of psychological symptoms. (Sabik, 2010). Thus, controversy about this disorder continues to be an issue. There has been some speculation that there are external triggers associated with fibromyalgia. Some of these include chronic infection (Epstein-Barr virus, Lyme disease, viral hepatitis [Clauw, 2014]), vaccination, physical and/or psychological trauma. These triggers are not only associated with a sudden exacerbated stress response, but also a prolonged stress exposure. The dysregulation of the Autonomic Nervous System (ANS) (associated with the stress response) has also been shown to be connected to other autoimmune diseases as well. The effects of trauma and stressful life events will be further discussed later; however, it is noted that there are suggestions of physiological consequences of abuse and neglect (Palm & Follette, 2011). A question that has been postulated through many of the physiological findings is: how does trauma, or psychosocial stress put people at risk for later disease? One theory states that stress, specifically childhood stress, creates a pro-inflammatory response in cells of the immune system (Hellou et al., 2017).

The link between FM and both physical and psychological trauma, illness and injury are attributed to the associations and the significant impact that stress plays on the brain. Prolonged stress in particular has proven to cause immune dysregulation and can impact neurotransmitters responsible for the modulation and

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perceptions of pain. (Lundervold et al., 2006). This has been linked through physiological research that suggests that when humans are stressed our ANS becomes dysregulated, creating adverse effects. This in turn causes the Hypothalamic Pituitary Adrenal axis (HPA axis) to become dysregulated (Martinez-Torteya et al., 2016), and either release an influx of hormones that are associated with autoimmune disease, or blunt the release of stress hormones that enhance the use of bodily function, such as heart beat or breathing (Lundervold et al., 2006; Obasi et al., 2017). When under stress the HPA axis releases an excess of a chemical called glucocorticoids that create a negative feedback effect on biological mechanisms. When an individual experiences a trauma or multiple stressors, the HPA axis becomes limited in its usual physiological situations. If the HPA axis does not function properly, then those with trauma, stress or other mood disorders, have the potential to overly react or not react when necessary to physiological stress. For instance, those who experience trauma or stress in utero or childhood were found to have either externalizing (hypoactive stress response; disruptive behavior, attention problems, hyperactivity) or internalizing (hyperactive; depression, anxiety) HPA axis activity (Martinez-Torteya et al., 2016). This suggests that stress leads to overall neuronal dysregulation, not just reactivity.

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In conjunction with overactive release of stress hormones that harm the body, there are also hormones that are helpful in typical autonomic functioning. Cortisol, which is released through the HPA axis is also associated with increasing the functioning of things like the cardiovascular system, anti-inflammatory response of the immune system and changes in glucose metabolism (Obasi et al., 2017). If there is an influx or lack of these hormones it would impact basic heart and immune functioning, creating disruptions within the body. When the body is under stress and attempting to return back to homeostasis it creates wear and tear on the body (Obasi et al., 2017), which is consistent with the hypothesized functions behind FM.

The cells in the HPA axis, hypothalamus and pituitary gland are then permanently changed and have pro-inflammatory tendencies (Obasi et al., 2017). These cells have a decreased sensitivity to inhibitory signals, so when there is a threat or a heightened response the individual struggles to decrease or stop the response. This leads to the prolonged experience of stress that is typically harmful. Due to the prolonged stress, it can lead to an individual who is more hypervigilant than most, has difficulties with trust and finds it difficult to form social ties, creating a cycle of overactivity in above named brain regions. Yavne et al., (2008) also indicated that negative life events appear to change brain circuitry and result in spontaneous nerve activity. However, much research is needed in that area as well

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as in the biological sciences to understand what else is contributing physiologically to the condition.

The pain in FM is referred to as a centralized pain state, meaning that the central nervous system (CNS) is the origin of pain and also creates the amplification of pain (Clauw, 2014). The cardiovascular system and genetic components are also associated with an elevated stress response, and the dysregulation of the CNS has continued to be closely followed in this disorder (Palasynski and Nemeroff, 2009; Sabik, 2010). Due to the dysfunction of the central nervous system (CNS) (which then disrupts the ANS), individuals who are diagnosed with FM are believed to feel more pain than a healthy individual because of the input they receive from the central nervous system (Clauw, 2014). The term “centralization” denotes that nociceptive input is responsible for part of a person’s pain, but the dysregulation of the CNS likely amplifies the pain. The disrupted levels of neurotransmitters create more pain for a person with FM.

Additionally, the disruption in the same neurotransmitters that contribute to pain are also linked to fatigue, memory problems, sleep difficulties and mood disturbances (Clauw, 2014). FM patients suffer from neuropathic pain and can be hypersensitive to something as small as a pinprick or temperature changes. This is described as an over-excitatory response of neurotransmitters such as glutamate, and a decrease of serotonin, norepinephrine, and gamma-aminobutyric acid

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(GABA), in the cerebrospinal fluid (CSF). This is suggestive of a dysregulation of both pain response and the endocrine system (Yavne et al., 2018).

Psychological Factors

Various psychological disorders have been associated with FM. Some of those diagnoses include depression, anxiety, panic disorders, post-traumatic stress disorder (PTSD) (Buskila & Cohen, 2007), and recently bipolar related disorders, eating disorders, substance use disorders (Arnold et al., 2006), as well as maladaptive personality profiles (Fietta, Fietta & Manganelli, 2007). The question still remains whether chronic pain that is involved in FM causes depression, or whether depression or other mood disorders lead to FM (Buskila & Cohen, 2007). Previous research has indicated that there is a statistical relationship between chronic pain and depression; however, the causal nature of the relationship remains unknown (Fishbain, Cutler, Rosomoff & Rosomoff, 1997). Individuals diagnosed with FM were reported to have higher rates of mood and anxiety disorders (Arnold et al., 2006), while an estimated 30% of patients with FM meet criteria for Major Depressive Disorder (MDD) at the time of diagnosis (Buskila & Cohen, 2007). Furthermore, a study done to find any links between MDD, and FM found that current MDD was almost three times more likely in women with FM compared to those without FM (Buskila & Cohen, 2007). In addition to mood disorders, anxiety

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disorders such as panic disorders, social phobias, and obsessive compulsive disorders are associated with FM (Arnold et al., 2006). When assessed for lifetime risk, Buskila and Cohen (2007) found that women with FM had higher prevalence rates of anxiety disorders compared to matched controls.

It is hypothesized that those with FM are not more likely to have greater negative affect, but they are more likely have dysfunctional mood regulation (Fietta, Fietta & Manganelli, 2007). Arnold et al. (2006) observed that psychological diagnoses preceded the onset of FM in the majority of cases. In addition to mood disorders, a study was done to evaluate the levels of functional impairment and levels of psychological distress on FM patients. Epstein et al. (1999) found that FM patients had higher levels of lifetime psychiatric disorders and significant current psychological distress. Lastly, it is suggested the perceptions of having FM – the idea of functional impairment and pain – play an important role in predicting symptomology because of negative connotations associated with the illness (Buskila & Cohen, 2007).

Previous research had suggested that pain related acceptance helped individuals enhance their physical and emotional functioning, specifically in patients who suffered chronic pain (Geiser, 1992). Perceived levels of stress are also another factor that likely contributes to FM patients experience of pain and ability to complete daily tasks. If an individual has significant stress and

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discomfort, then they may not want to engage in daily activities. Stress, depression, and lower life satisfaction would likely exacerbate pain symptoms for someone with FM, further contributing to the painful cycle they endure. Creating a positive sense of well-being and self-esteem would be the optimal target for patients struggling with FM symptoms and acceptance. Karoly and Jenson (1987) argued that individuals who are diagnosed with a chronic pain disorder have a tendency to develop self-defeating attitudes about their pain in relation to accomplishment of desired goals. This can result in a general lower level quality of life.

Prolonged and exacerbated stress could be hypothesized to be a trigger for autoimmune diseases due to the links between stress and physiological reactions within the brain and body. If an FM patients' pain is neuropathic and stress exacerbates the bodies response to daily activities, patients with FM who also utilized avoidant coping strategies would be more likely to struggle with everyday activities. Lack of social ties could also be detrimental to the health and well-being of FM individuals, depending on the severity of their illness (Miller et al., 2011). The reason being that, those with more social supports typically live longer and healthier lives (Holt-Lunstad, Smith & Layton, 2010). If an FM patient has a spouse, family, friends or other supports of that nature they will be more likely to not only take better care of themselves but perceive they have help with daily living, should they need it.

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Behaviorally, being aware of one's experience can change the idea or perception of what is known about the event, experience, or situation. If we alter the way we view the event or our behavior it can change our reaction to it. When a person thinks of their experience or emotion as "bad," we associate those uncomfortable feelings with it. This is the idea behind most third wave therapeutic orientations such as ACT and cognitive behavioral therapy (CBT). Through the process of identification and acceptance it can become easier for anyone, not just FM patients, to modify emotions and negative thought patterns to improve overall psychological functioning.

Stigma

Unfortunately, a significant amount of stigma surrounds FM. Both the symptoms and the overall existence of the disease has been questioned (Sabik, 2010). There has been research that has substantiated findings regarding altered neurotransmitters and differing activity on brain scans for those who report symptoms that appear as FM; however, friends and loved ones still often doubt the diagnosis due to the lack of physical changes in the FM patient. Due to the difficult nature of the diagnosis, the symptoms of patients are frequently discounted by physicians and insurance providers alike (Sabik, 2010). Another reason there is

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doubt regarding FM is because it is an “invisible illness”, meaning that at first glance it is not evident that a person is sick at all. Someone who has a diagnosis of FM likely would look healthy on the outside but may be constantly battling with their pain. If a disease or injury is not immediately evident such as with a broken bone, or a physical disability like paralysis then people often believe an individual is not impaired or ill, or even embellishing their complaints. When this happens those around an FM patient tend to dismiss their symptoms as overexaggerated complaints. FM patients are frequently viewed as lazy or a fraud, and this judgement can lead to negative perceptions of themselves (Sabik, 2010).

Trauma

Fibromyalgia has been theorized to be exacerbated by external factors such as stress, interpersonal problems, emotional dysregulation or trauma (Lumley et al., 2008; Yavne et al., 2018; Lundervold et al., 2006). In fact, childhood maltreatment (e.g. emotional abuse, neglect), physical trauma, psychological trauma, or other life events have frequently been reported in individuals diagnosed with fibromyalgia (Lumley et al., 2008; Yavne et al., 2018; Hellou et al., 2017). Along with that, women who have a history of childhood sexual abuse have been found to have an increase in psychopathology and they were more likely to suffer more trauma-related symptoms (Palm & Follette, 2011). Experience of trauma is an important

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variable to consider due to the frequent reports from patients with fibromyalgia that they have experienced a negative life experience (Buskila & Cohen, 2007). As noted above, previous research has postulated that individuals with FM have higher stress responses or trouble with coping skills because of an inability to regulate emotions or poorer psychological adaptation.

Experiential Avoidance

Experiential avoidance is defined as an unwillingness to experience unwanted internal experiences or private events. Unwanted experiences may include bodily sensations, emotions, thoughts, memories, or behavioral predispositions (Hayes, Wilson, Gifford, Follette & Strosahl, 1996). This phenomenon is also referred to as psychological inflexibility and can be associated with maladaptive behavior such as substance abuse, social isolation, self-harm, other ineffective behaviors. This process is generally associated with avoidance of unwanted thoughts and the attempts to suppress thoughts can create several unintended effects (ex. anxiety, depression, somatic symptoms) (Gootzeit, 2014). Attempting to avoid unpleasant or painful thoughts, events or feelings could be helpful in the short run; however, by focusing on pushing it out of consciousness, a rebound effect is actually found and an increase in these unwanted experiences is demonstrated (Hayes et al., 1996). McCracken, Vowles and Eccleston (2004) found

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that acceptance of chronic pain enhanced the emotional and physical functioning in patients. Interestingly, patients who felt it was unnecessary to control pain to pursue goals and values used less health care, evidenced less distress and were more likely to be working. This in turn alleviated pain intensity, depression and improved coping (McCracken, Vowles & Eccleston, 2004).

The reason in which humans typically avoid these events or emotions is because they are viewed as negative or “bad” emotions (Palm & Follette, 2011; Hayes et al., 1996). Because we can describe and not just feel the events, this creates a stronger sense of aversion; when an individual talks about a traumatic experience it brings them back to those memories, thoughts, and feelings (Hayes et al., 1996). With all of the research and information discussed there is no wonder people typically attempt to evade these feelings – they are uncomfortable. However, this avoidance can lead to a rigid and inflexible way of dealing with life that can actually exacerbate problems.

The idea of psychological flexibility is associated with experiential avoidance. Psychological flexibility is described as being able to approach situations separately and contextually, while also being more flexible in the way the event is perceived and responded to. Psychological flexibility is associated with experiential avoidance because as psychological flexibility decreases, it would be assumed that the idea of more rigid rules and the feeling of the need to control or

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avoid negative experiences increases. When those with low psychological flexibility engage in potentially dangerous or ineffective behaviors, life becomes a cycle of avoidance. The individual may continue to feel rigid in their thinking patterns and how they interpret their experiences and are fearful and avoidant of feeling any kind of distress, and in turn engage in the maladaptive behaviors. As this cycle continues, they are less likely to live a valued life.

A study done with children with Juvenile Primary Fibromyalgia Syndrome (JPFS) found that those who were able to think more rationally about their pain – meaning they were able to put it into perspective and not allow it to stop them from engaging in hobbies - and exhibited stronger coping abilities experienced lower levels of pain and had lower levels of physical or psychological distress (Libby & Glenwick, 2010). This information suggests that while FM likely has a biological component it has a psychological component as well and links psychological flexibility to more desired outcomes. If the psychological component does exacerbate an illness like FM, then one hypothesis to assist individuals with the diagnosis could be to improve their coping or emotional regulation. Ideally, it would assist in lowering physical symptoms, enable patients to engage in activities despite pain, and lessen the risk for developing the illness. Similarly, with trauma and stress – if a patient with fibromyalgia has experienced a trauma, stress would contribute to exacerbation of symptoms and continue to amplify existing problems.

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This can lead to a cycle of avoidance in an attempt to manage both physical and psychological symptoms.

It has been suggested that the patients with FM are more experientially avoidant and have poor emotional regulation (Hayes et al., 1996). If in fact psychological factors are associated with FM and patients who are more inclined to avoid private experiences they perceive as negative, this can actually result in pain symptoms being further exacerbated. The pain or FM symptoms lead to patients not engaging in previously enjoyed activities, they could become frustrated, angry, or depressed. This could lead to an increased risk of physical symptoms and creating their own negative feedback loop between physical symptoms and psychological distress. It is easy to understand why a person with a chronic illness may avoid activities more than a healthy individual: their life has changed, and they have to find adjustments to accommodate themselves and their illness. Acceptance is an active process; it is something that must be worked toward in a myriad of situations. If approaching chronic pain in active manner and accepting aids in maintaining functioning then, the opposite is likely true – a passive and avoidant approach would encourage losses or decrease in functioning (McCracken, Vowles & Eccleston, 2004).

In regard to goal directed behavior and individuals who suffer chronic pain, it is observed that they develop what is referred to as a “self-defeating

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schema” or fusion with negative beliefs about the self (Affleck et al., 2001; Hayes et al., 2004). This is the concept that the disease, chronic illness, or pain hinders someone from valued living or moving forward with goals. The reason for this is due to the perception the individual has regarding their pain and the belief that the pain means that valued living is not possible (Hayes et al., 2004). Another study that examined goals and human motivation found that perception of the goal, previously attained goals, and personality characteristics play a role in perception and ability to engage in tasks to complete goals (Karoly & Ruelman, 1995). Experiential avoidance and perceived levels of stress are two important variables that have the potential to impact FM. The ways in which they can be measured and how they impact this illness will be further explored.

Value Based Behavior

Acceptance and Commitment Therapy (ACT) created by Stephen Hayes is a third wave therapy modality that encourages people to live more closely to their values. The creators of ACT have defined values as “chosen qualities of action patterns that people can work toward but that they cannot arrive at once and for all” (Bond, Hayes & Barnes-Holmes, 2006). Values involve verbally constructed contingencies that assist and motivate individuals toward goals and living an effective life. It also encourages people to feel their anxiety or distress and

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experience any negative feelings rather than pushing it away so you can find what you value and make the choice congruent to those values (Pearson, 2006). Most people struggle to live a life consistent with their values and address their feelings of anxiety, and stress (Hayes et al., 2004). This relates to ideas around goal directed behavior because should an individual with chronic pain perceive their pain or symptoms as more severe or a barrier to their goals, then they will be less likely to engage in that goal directed behavior.

Often when an individual is asked about their values, they may struggle to know the difference between a value and a goal. The difference is that goals are actions that have finality, such as going to the doctor. Values are a direction, such as living a healthy lifestyle. Goals are in the service of important client values (Bond, Hayes & Barnes-Holmes, 2006; Harris, 2018). Acceptance and Commitment Therapy asks individuals to examine their values and ask if they are living consistently with them. The difficult nature of this process can lead to avoidance and a lack of commitment to change, because it forces individuals to face uncomfortable thoughts and emotions. Those diagnosed with FM perceive that they are not able to participate in valued activities because of their condition, including the inability to sustain activities for long periods of time. Assisting patients with FM in identifying values is essential in living a fulfilling life. It is important to be flexible in identifying goals as they may change because of

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contextual factors such as having a chronic disease. Rules usually say what we cannot do rather than what we can do. Being more open and living through values of what you can do leads to more acceptance as well as helps someone live a life that helps make them happy and fulfilled. Values are identified by the patient deciding what is most important and acting on that (Harris, 2018).

Patients with FM may have more difficulty than others overcoming personal barriers and engaging in valued behavior or goals. From this, it could be postulated that an individual with a medical diagnosis would have further challenges attaining personal goals because one may assume that their view of their symptoms and limitations would hold them back from previously valued behaviors. Individuals diagnosed with chronic illness have other barriers to consider. Whether they can physically engage in an activity and, if so for how long, and what should be considered moving forward are all real issues. All of these variables taken together could result in clients with a medical diagnosis such as fibromyalgia becoming more avoidant and having difficulty in engaging in behaviors that would be medically beneficial to their psychological health. It would likely be assumed that those with higher levels of experiential avoidance, perceived stress, and more pain symptoms would be less likely to live a life congruent to their values and therefore experience more anxiety and symptomology related to their diagnosis.

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An individual with FM may grieve the loss of the previous capabilities due to the lifestyle modifications that may be needed. Specifically, the level of functioning they may have had prior to the illness may not be the same following the diagnosis, as well as the adjustment to learning new limitations (Acker, 2008). The ability to assist those diagnosed with FM in engaging in health behaviors or goal directed behaviors can be challenging. Additionally, patients may avoid valued-based behavior, or medical recommendations because they do not fully understand their diagnosis or the rationale for the suggested life changes.

Affleck et al, (2001) studied valued behaviors and goals in a sample of women with pain or medical disorders. Utilizing a daily journal, self-report questionnaires regarding goals and attitudes, and pain and fatigue questionnaires, authors took this idea of self-defeating attitudes in pain or a medical disorder and attempted to find who was more likely to engage in valued behavior or goals. Researchers hypothesized that those with more self-efficacy and natural dispositional optimism would be more likely to engage in goals that are of value to them. It was concluded that those with higher dispositional optimism were more likely to engage in values-based behaviors that assisted them toward life goals. The difficulty can be that optimism can be viewed as a trait that is difficult to change. However, there is strong empirical evidence that experiential avoidance can be

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targeted and that changes can be associated with increased willingness to engage in valued behavior.

Current Study

While FM has been studied for many years, there continues to be questions regarding ways to support clients in dealing with this disease. This study focused on assessing factors that can impact the quality of life for individuals with FM. Specifically, I explored the relationship between experiential avoidance and living a life according to one's values. FM often has large and lasting impacts on overall quality of life and in valued areas of an individual's life including with family, romantic relationships, and work life. The empirical literature suggests that not engaging in valued activities can exacerbate physical and psychological symptoms. This pattern of distress and avoidance of activities can become cyclical and lead to more difficulties over time. (Steiner, Bogusch & Bigatti, 2013).

The goals of the current research are to extend existing knowledge regarding value directed behavior, and barriers to living a life consistent with personal chosen values in individuals with FM. The study will also evaluate the roles of stress, impact of FM symptoms, and levels of acceptance of chronic illness. These variables will be addressed due to the associations between depression, perception of pain and its impact on engaging in not only everyday activities but

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enjoyed or valued activities as well. For the current study, several self-report measures will be utilized. The measures include the Fibromyalgia Impact Questionnaire-Revised, Patient Health Questionnaire 9, Perceived Stress Scale, Chronic Pain Acceptance Questionnaire-Revised and the Personal Values Questionnaire II.

1.) It is predicted that those individuals who rate higher on the measure of FM that assesses both symptoms and impact on functioning will indicate less valued activity and acceptance. They will also be more likely to report higher levels of perceived stress.

2.) It is specifically hypothesized that individuals who are more avoidant will be less likely to engage in valued behaviors and will report higher levels of psychological distress. .

3.) It is also hypothesized participants will be less likely to report living a valued life and more likely to report that they believe FM affects their ability to live a life to their values.

Methods

Procedure, Participants & Data Collection

An institutional Review Board at a private university approved this study. An online crowdsourcing marketplace was used for the current research was

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Amazon Mechanical Turk (MTurk). The website allows businesses and individuals to outsource projects and recruit workers to complete Human Intelligence Tasks (HITs) and earn money for their work. Prior studies have found that research results conducted through MTurk were almost indistinguishable from in-person participation results. There are numerous benefits to using MTurk, such as quick recruitment of a diverse sample. Additionally, because of the privacy associated with completing surveys online it has been suggested that participants were more willing to disclose mental health information (Casler, Bickel & Hackett, 2013). However, some questions remain about the utility of this mechanism for recruitment in assessing clinical samples. Participants are paid for their work and thus may be more motivated by that than providing accurate data. Participants were accepted regardless of their worker rating scores. Only those who self-identified as being 18 years of age or older and who had a diagnosis of FM were asked to participate in the survey.

Recruitment. The study advertised on MTurk was listed as a “Survey asking about Fibromyalgia, Fibromyalgia symptoms, quality of life, and ability to engage in valued behavior/activities. 18 years or older.” MTurk participants could preview the advertisement and were provided with information regarding eligibility, compensation, and time commitment for completion.

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Participants were advised that the study requires them to have a diagnosis of Fibromyalgia.

Procedure. Participants were routed from the MTurk website to an online survey created in Qualtrics, a web-based survey tool utilized for data collection. Participants were required to read and sign the informed consent, which includes information about the study content, confidentiality and contact information for the researchers.

The participants were informed that they would participate in a research study being completed by a doctoral student, and that they were able to opt out of the survey at any time. No identifying information was associated with the survey responses participants completed. Following acceptance of the informed consent, self-report inventories regarding their physical health, FM symptoms and functioning, perceived stress, pain avoidance, and valued behaviors were completed.

Participants. Demographics for all participants are listed in Table 1. The participants in this study were 134 adults (57 females [42.5%], 77 males [57.5%]) who reported having a diagnosis of FM. Ages ranged from 23 to 68 with a mean of 38 years. Ethnicity of participants was evaluated and notably, 49.3% identified as Asian/Pacific Islander and 33.6% as Caucasian. This is somewhat surprising as there is no noted relationship between Asian ethnicity and the occurrence of FM.

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This finding may be a function of the recruitment platform utilized and will be elaborated on later. The majority of the sample was married (61.9%) and 27.6% were single. The most common length of time since FM diagnosis was 1-3 years with 14.2% reporting a diagnosis within the last year, 56% within the last 1-3 years, 23% within the last 4-6 years, 2.2% within the last 8-10 years and 3% over ten years ago. Of the participants 90.3% reported being employed full time, 4.5% reported being employed part time, 1.5% reported unemployment, 1.5% reported being unable to work or disabled and 0.7% reported they were students, homemakers or retired. Interestingly, 45.5% of the sample reported they were currently seeking psychotherapy for problems related to their FM diagnosis and 41.8% reported they had sought psychotherapy in the past for problems related to FM.

Following the demographics questionnaire, participants completed and each of the standard measures, detailed below. If the individual was unable to complete the survey in one sitting, they were allowed to save the data and go back later. However, if the survey was never completed, they were not compensated for their work.

Measures

Fibromyalgia Impact Questionnaire-Revised (FIQ-R). The FIQ-R was developed to evaluate the current status of individuals diagnosed with FM. It

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assesses both FM symptomology and impact on functioning. This included various aspects of their everyday life such as, physical functioning, psychological distress, pain, sleep, stiffness and well-being (Wicksell et al., 2013). The FIQ-R is broken into three domains (functional, overall impact, and physical symptoms). Within each domain there between 3 – 10 questions that are answered on a 10 point likert scale, ranging from 0 – 10 (0 = no difficulty; 10 = very difficult). Scores range from 0-100, with higher scores indicating greater symptom severity (Simister et al., 2018). The measure contains three subscales within the questionnaire: function, impact, and symptoms (Bennett, 2009). The three domains are then added together to create a total score. The FIQ-R demonstrates good reliability and validity, appears sensitive enough to pick on changes in treatment changes and has been used extensively in FM research (Wicksell et al., 2013). For the current study, the total score was used for statistical analyses.

Patient Health Questionnaire 9 (PHQ-9). In order to measure depression and psychological symptoms in medical settings, the PHQ-9 was developed. It is a nine item measure of depression with a likert scale from 0-3 (0 = not at all; 3 = nearly every day). The PHQ-9 scores range from 0-27 and a score of eight or above indicating depressive symptoms (Graham et al., 2016). The PHQ-9 is brief and has demonstrated adequate validity making it an appropriate dual purpose instrument for assessing depression severity and general distress (Kroenke et al., 2001). The

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developers of the measure reported that this measure is associated with functional status, disability days, and symptom related difficulties that are associated with depressive disorders (Kroenke et al., 2001).

Perceived Stress Scale (PSS). PSS is a measure of perception of stress in regard to daily life (Murray et al., 2006). Cohen et al (1983) based it on the idea that the perception of stressful life events has a more profound effect on health than the actual event itself. It also is intended to capture the individual's perception relative to their ability to cope. The PSS is a 10-item measure that asks people to rate their daily stress within the last month on a likert scale ranging from 0-4 (0 = never; 4 = very often). Scores on the PSS range from 0-40, with higher scores suggesting higher levels of stress (Murray et al., 2006). Psychometric analysis of the PSS indicated adequate reliability and validity (Taylor, 2014).

Chronic Pain Acceptance Questionnaire - Revised (CPAQ-R). The CPAQ-R was primarily designed as a measure to quantify acceptance in pain populations. Geiser (1992) based the AAQ on an assessment of emotional avoidance developed by Hayes et al., 2003. Two factors are included in the measure: activity engagement, and pain willingness. The questionnaire includes twenty questions based on the two factors. The items are scored on a likert scale from 0-6 (0 = never true; 6 = always true). High scores indicate higher levels of acceptance of pain and involvement in activities. The CPAQ-R was shown to have adequate internal

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consistency and findings supported the factor structure of the measure. The CPAQ-R demonstrated high reliability values and indicated correlations between pain, emotional distress, and patient functioning (McCracken and Vowles, 2008). Additionally, authors reported that the activity engagement and pain willingness factors were able to predict pain related disability and distress (McCracken, Vowles, & Eccleston, 2004).

Personal Values Questionnaire II (PVQ-II). The PVQ-II was developed as an Acceptance and Commitment Therapy (ACT) measure based on the Personal Strivings Measure (PSM) by Kennon Sheldon and colleagues (Blackledge, Ciarrochi & Bailey, 2006). It measures the nine domains of values that ACT emphasizes (family, friendships/social, romantic relationships, work/career, education/personal growth & development, recreation/leisure, spirituality/religion, community, health/well-being) and how closely individuals are living in accordance with their values. Individuals are asked to write down their value to each area before completing the rating scales. Within the nine domains there are 5 questions and individuals are asked to answer a likert scale of 1-5 (1 = not at all; 5 = extremely so) based on the importance of that value and whether or not they have been living this value. Individuals are meant to consider what they value within each domain and rate accordingly. (Hayes, 2005; Blackledge, Ciarrochi & Bailey, 2006). For this study, a question was added to assess the impact of FM.

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Specifically, a question asking about the role fibromyalgia plays on their ability to live those values was added. For this study, we analyzed the data for two questions. Item 4 asked whether fibromyalgia had impacted the ability of the participant to live consistently with the valued domain. Higher scores indicate FM had a negative impact on living values. Item 5 asked how successful the participant had been in living this value in the past month. High scores indicate that someone has been successful in living values.

Results

Prior to analyses, data was examined for accuracy of data entry, missing values, repetition of participants and fit between the distributions. Missing values occurred infrequently; however, there were multiple unfinished surveys. The participant data were included, except when a particular measure was used that was not completed.

Initially, bivariate correlations (Table 2) were run to examine the relationships between the self-report measures of FM impact, symptoms and functioning, activity engagement, pain willingness, overall psychological health, perceived stress and constructs that assess values and ability or willingness to live those values. The subscales (pain willingness & activity engagement) of the Chronic Pain Acceptance Scale were strongly positively correlated ($r=.78, p<.01$),

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indicating that higher levels of activity engagement were associated with higher levels of avoidance. This is counter to our hypothesis. Because of this, additional analyses were conducted using the subscales of the measure. The impact, symptoms and functioning of FM was positively correlated with activity engagement ($r = .49, p < .01$) meaning that those more impacted by FM were more engaged in activities, contrary to our expectation. In terms of pain willingness, it was also positively related to FM impact ($r = .49, p < .01$), indicating that higher rates of avoidance were associated with higher FM impact. Psychological health/depression (PHQ-9) was positively related to FM impact ($r = .45, p < .01$) as was stress ($r = .39, p < .01$). That is, those with higher rates of stress and depression reported more impact of their FM.

Item 4 on the PVQ assessed the impact of FM on the ability to live a value and item 5 assessed the ability of the person to live their value in the last month. Theoretically these should have been negatively correlated, however surprisingly they were positively related ($r = .49, p < .01$). This could be a function of participants failing to detect that this item was reverse coded, or essentially misunderstanding the question. The question on how much fibromyalgia impacted PVQ-II question regarding FM's impact on valued living (values question 4) was positively related ($r = .21, p < .01$), which was predicted. However, there was no correlation between

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FM impact and the PVQ-II question regarding success in living the value (values question 5) ($r = .04, p = .67$).

A hierarchical multiple regression analysis was conducted to examine how impact of FM, activity engagement and pain willingness predicts an individual's ability to live according to their values (Table 3). The first regression model included only the FM impact variable. The one predictor model specified the first regression model was significant, $F(1,95) = 4.64, p < .05$, with a reported $R^2 = .05$, and indicated that the impact of FM was a positive predictor of the impact of FM on the ability to live ones' values. The second regression model included FM impact and entered two additional variables related to value based behavior – Activity engagement and pain willingness – to determine if either of these two scores were unique predictors of ability to engage in value based behavior beyond the impact of FM. Based on change statistics, findings showed that the more complex model was a better overall predictor of ability to engage in value based behavior, $\Delta R^2 = .18, F_{change}(3,93) = 8.80, p < .01$. The change in R-squared indicates that the second model predicted 17% more of the variability in an individual's ability to engage in value based behavior than in the first regression model. However, there were concerns with multicollinearity between the three predictors. As seen in Table 3, the second regression indicated that FM impact ($\beta = -.03$), and activity engagement ($\beta = .16$) were not unique overall predictors of

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ability to engage in value based behavior. Although Pain willingness ($\beta = .35$) was a stronger overall predictor of value based behavior. This may suggest that the variables - FM impact, pain willingness and activity engagement – taken together are too similar in their constructs or what they are measuring. Moreover, this finding was counter to our hypothesis and is subject to the same concerns observed in the correlation analyses.

Discussion

Fibromyalgia is a debilitating and life changing disease. The current study served to further investigate the link between FM impact, psychological health/depression, stress perceptions and individual's willingness to engage in valued behavior. The goals of the overall research were to investigate the impact of FM, levels and perceptions of stress, psychological well-being and acceptance, and how these variables impact reports of living a valued life. Research is needed not only about the medical treatment of FM, but also about psychological care including factors that might be targeted in treatment. Some studies have made observations between trauma, FM diagnosis and experiential avoidance. However, few studies have examined the relationship between FM impact, acceptance, ability and success in living valued behavior.

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It was hypothesized that those who experience more significant symptoms of FM will have less acceptance of their pain, experience higher levels of perceived stress and more significant psychological symptoms. There were several anomalies in the data which are discussed in the limitations section. Therefore, all analyses should be considered with caution. Depression, stress, and FM impact were all positively correlated, supporting the hypothesis that symptoms and functional impact of FM were associated with higher levels of depressions and stress. This is consistent with the literature and supports the need for psychological intervention for individuals suffering the chronic and debilitating disease of FM. Overall, those with higher impact of their FM reported that higher FM scores. However, there was no relationship between FM impact scores and valued living in the last month. These findings are mixed and add to further questions about the validity of the data. If one rated a negatively impact of FM on living values, it is surprising that they would state they were able to successfully live a valued life in the last month.

Statistical analyses demonstrated that the subscales of the CPAQ were positively correlated in the wrong direction. Specifically, pain avoidance was correlated with engaging in activities. This counterintuitive finding has not been found in the literature. Thus, while there were some significant correlations with depression, FM Impact, stress and values, these findings should be interpreted with great caution. Depression was significantly correlated with FM impact, perceptions

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of stress, ability to engage in valued behavior and success in valued behavior. The FM impact score significantly correlated with stress and ability to engage in valued behavior, but there was no correlation with success in living the values. Finally, stress was significantly correlated with ability to engage in value behaviors and success in living valued behaviors; while ability and success in valued based behavior were also significantly correlated. While some of the findings were supportive of the hypothesis, the main findings contradict the literature that has been previously done on these subjects.

As noted in the introduction women are more likely than men to be diagnosed with FM than men. Prior research postulates many reasons for this: women are more likely to report symptoms, women are more likely than men to go to the doctor and men are less likely to persist following uncertainty from their doctor (Lumley et al., 2008). However, in the current study there was an interesting phenomenon – the demographics breakdown showed that 42.5% of the participants were female and 57.5% were male. There were 15% more male participants than female. While this is not a limitation, it is interesting to note. It is possible that men are more likely to participate in online based research, compared to face-to-face or live research that requires divulging private or intimate information.

Further demographics information may have impacted the statistical significance of the hierarchical multiple regression results. An individuals ability to

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live according to their values or engage in value based behavior is likely impacted by many factors – not just illness. The participant population was also largely younger in age. There is less research regarding age and FM, so it is difficult to say whether or not age plays a role. If normal aging is considered, younger people would likely be more apt to engage in joyful activities or hobbies of interest. However, most participants stated that their FM did impact their ability to live valued behavior. It is odd though, that acceptance of chronic illness was seen at a higher rate. Repeating this research in a live study rather than an online survey may assist in any discrepancies regarding high reports of acceptance along with higher reports of FM impacting value based behavior.

Participants were also asked the time since their diagnosis. They were given multiple date ranges and asked to select which applied to them. A majority of participants endorsed being diagnosed within the last three years. It would be interesting to look further into the time since FM diagnosis and if that impacts individuals' perceptions or lifestyle. One might assume that those who had been diagnosed more recently would be attempting to continue with activities that they engaged in prior to diagnosis. Also, that the patients who are newly diagnosed would still be working through the acceptance aspect of chronic pain, not endorsing higher levels of acceptance.

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Limitations

There are several limitations to this study. The first being the data collection was conducted on a crowd sourcing website. There can be issues with using this format for collection of clinical data. It is likely that younger people are more prone to utilize online survey services compared to older populations and this is demonstrated in the high number of younger participants. Therefore, many of the older participants who may be more likely to have significant struggles with chronic illness may not have been sampled. The researcher also failed to add a question to ascertain the attention of participants leading to questions about the accuracy of the data. Some findings are counter intuitive, and this may represent carelessness of the part of participant responding. Given that MTurk is a paid task and participants respond quickly to maximize earnings, there may be questions regarding the engagement of the participants in the task. Moreover, it was required that participants indicated that they had been diagnosed by with FM by a medical physician. However, there was no way to obtain confirmation of the diagnosis so this may be another issue. It would have been better to use a listserv specific to patients with FM because they might have more investment in the project. The researcher did approach two organizations for access to their listservs, however both requests were denied.

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Additionally, the Personal Values Questionnaire II (PVQ-II) was the first survey given and due to some of the responses regarding the participants individual values, participants may not have comprehended the meaning of values or not read the instructions correctly. This leads to some questions about the way in which participants answered the questions regarding the values they listed. Frequently participants would leave the write in portion of the values question blank, and thus the likert ratings of the questions may not be accurate representation of how the measure is to be used. Further research on the use of the measure in surveys may be needed. It may suggest that the PVQ-II is better suited as a clinical tool, rather than a research tool. Having a researcher or clinician actively involved with the participant to explain values to those who are unsure and to make sure participants are following the instructions is part of the reason it may be better suited as a clinical tool. The instrument has been shown to have clinical utility however use in this type of sampling may be more problematic.

Along with the limitations, there are other discrepancies that are worth noting. A trend that is typical in research is the lack of diversity. Most populations surveyed are Caucasian and middle class. The data in the current study indicated that almost half of the participants who completed the FM survey on Mturk were Asian/Pacific Islander. There has been little research on the presence of FM in ethnicities besides Caucasian and there is no indication in the literature for a higher

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prevalence of the disease in Asian populations. Further research on FM in other populations and ethnicities would be important in the future to better understand the diagnosis. However, there has been research regarding the use of MTurk among various populations and genders. When MTurk was originally established a majority of the workers were based in the U.S. and overtime that number has changed dramatically (Ross, Irani, Silberman, Zaldivar & Tomlinson, 2010). As of 2014 demographic surveys have demonstrated that MTurk is dominated by workers residing within the U.S. and India, with less than a quarter residing elsewhere (Paolacci & Chandler, 2014). Various theories have been postulated regarding this information, but there is not necessarily a clear cut answer. Thus, the use of MTurk may have provided a biased sample.

Clinical Implications and Future Research

Based on the current study and its findings, future research on what hinders individuals from engaging in values or value based behavior would be important. The results that were gleaned from the current study also suggest that depression and stress are linked to a diagnosis of FM. It is likely some participants might have interpreted that the acceptance of chronic pain would equate to succumbing to the illness and “giving in.” That would mean that different people have different interpretations for what that might mean, and that giving into pain and accepting it may mean the opposite of what the acceptance measure was actually attempting to

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assess. There may have been participants that thought pushing through the pain, did in fact not mean the same as acceptance, but actually the opposite – not accepting the pain. While the CPAQ-R has been empirically validated and exhibits reliability, reading instructions through a web based survey still have the potential to be unclear.

The analyses of results also suggested that many individuals endorsed high perceptions of pain, stress, and depression, but noted they believe they are still able to engage in these values. If this is in fact correct, further research on those who are better able to continue to engage in daily tasks and activities with their pain would be both interesting and important for treatment.

Additionally, acceptance and activity engagement have been demonstrated to be important predictors of successful engagement in living a valued life with faced with a chronic illness. Further research with FM patients will help to understand how to provide the most clinically useful treatment for this important population.

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Appendix A Demographics

1. What is your age?
2. What is your gender?
 - a. Female
 - b. Male
 - c. Other
 - d. Prefer not to say
3. What is your marital status:
 - a. Single
 - b. In dating relationship
 - c. Married/In domestic partnership
 - d. Separated/Divorced
 - e. Widowed
4. What best describes your race ethnicity?
 - a. Black or African American
 - b. Hispanic or Latino
 - c. Native American or American Indian
 - d. Asian/Pacific Islander
 - e. White/Caucasian
 - f. Mixed/Multiple race
 - g. Other
5. What is the highest degree or level of school you have completed? If currently enrolled, highest degree received.
 - a. No schooling
 - b. 8th grade
 - c. Some high school, no diploma
 - d. High school or equivalent (GED)
 - e. Some college
 - f. Trade/Technical/Vocational training
 - g. Associate's degree
 - h. Bachelor's degree
 - i. Master's degree
 - j. Professional degree
 - k. Doctorate degree

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6. What is your current employment status?
 - a. Employed full-time
 - b. Employed part-time
 - c. Unemployed
 - d. Homemaker
 - e. Student
 - f. Military
 - g. Retired
 - h. Unable to work/disabled

7. What was your annual household income for the past year?
 - a. Less than \$20k
 - b. \$20k - \$40k
 - c. \$40k - \$60k
 - d. \$60k - \$80k
 - e. Above \$80k

8. When were you diagnosed with Fibromyalgia?
 - a. Within the last year
 - b. 1-3 yrs ago
 - c. 4-6 yrs ago
 - d. 8-10 yrs ago
 - e. 10+ yrs ago

9. Are you currently or have you ever sought psychological treatment from a therapist or psychologist for any mental health problems? Select all that apply
 - a. I am currently in therapy
 - b. I have sought therapy in the past
 - c. I have never attended therapy

10. Have you ever sought psychological treatment for issues related to your fibromyalgia diagnosis from a therapist or psychologist for any mental health problems? Select all that apply.
 - a. I am currently in therapy for issues related to my fibromyalgia diagnosis.
 - b. I have sought therapy in the past for issues related to my fibromyalgia diagnosis.
 - c. I have never attended therapy for issues related to my fibromyalgia diagnosis.

VALUED LIVING AND FIBROMYALGIA

Personal Values Questionnaire II

Following this instruction sheet, you will find 9 additional pages. Each page includes one of the Values Domains (areas of your life you may find important) listed below, in order.

Values Domains:

1. Family Relationships
2. Friendships/Social Relationships
3. Couples/Romantic Relationships
4. Work/Career
5. Education-Schooling/Personal Growth and Development
6. Recreation/Leisure/Sport
7. Spirituality/Religion
8. Community/Citizenship
9. Health/Physical Well-Being

On each page that follows, please read carefully through the values domain description and write down YOUR values (ways of living and doing things related to that Values Domain that are very important to you) where indicated.

Below each of the values that you write down, you will see a series of 9 questions asking different things about those individual values. Please answer each of these questions by circling the numbers that are true for you, on each page that you list a personal value.

Personal Value #1: Family Relationships

Instructions: If this is an area of your life that is very important to you, describe the person you would most like to be in your relationships with your parents, siblings, and/or children (do not include Couples/Romantic Relationships). For example, some people who want close relationships with these family members value being caring, supportive, open, honest, kind, and attentive—but you should decide for yourself what kind of person you value being in your family relationships.

Please write down your Family Relationships values here:

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Please answer the following questions by circling the number (on the right) that is true for you:

- | | | | | |
|----------------------------|---------------------------|----------------------------|--------------------|---------------------------|
| 1. Not at all
important | 2. A little bit important | 3. Moderately
important | 4. Quite important | 5. Extremely
important |
|----------------------------|---------------------------|----------------------------|--------------------|---------------------------|
1. How important is this value to you?
 2. How committed are you to living this value?
 3. Right now, would you like to improve your progress on this value?
 4. My Fibromyalgia has impacted my ability to live this value:
 5. In the last month, I have been this successful in living this value:

Personal Value #2: Friendships/Social Relationships

Instructions: If this is an area of your life that is very important to you, describe the person you would most like to be in your friendships and other social relationships. For example, some people who want close relationships with friends' value being caring, supportive, open, honest, kind, and attentive—but you should decide for yourself what kind of person you value being in your friendships.

Please write down your Friendships/Social Relationships values here:

Please answer the following questions by circling the number (on the right) that is true for you:

- | | | | | |
|----------------------------|---------------------------|----------------------------|--------------------|---------------------------|
| 1. Not at all
important | 2. A little bit important | 3. Moderately
important | 4. Quite important | 5. Extremely
important |
|----------------------------|---------------------------|----------------------------|--------------------|---------------------------|
1. How important is this value to you?
 2. How committed are you to living this value?
 3. Right now, would you like to improve your progress on this value?
 4. My Fibromyalgia has impacted my ability to live this value:
 5. In the last month, I have been this successful in living this value:

Personal Value #3: Couples/Romantic Relationships

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Instructions: If this is an area of your life that is very important to you, describe the person you would most like to be in a romantic relationship. For example, some people who want close romantic relationships value being caring, supportive, open, honest, kind, and attentive—but you should decide for yourself what kind of person you value being in a romantic relationship.

Please write down your Couples/Romantic Relationships values here:

Please answer the following questions by circling the number (on the right) that is true for you:

- | | | | | |
|----------------------------|---------------------------|----------------------------|--------------------|---------------------------|
| 1. Not at all
important | 2. A little bit important | 3. Moderately
important | 4. Quite important | 5. Extremely
important |
|----------------------------|---------------------------|----------------------------|--------------------|---------------------------|
1. How important is this value to you?
 2. How committed are you to living this value?
 3. Right now, would you like to improve your progress on this value?
 4. My Fibromyalgia has impacted my ability to live this value:
 5. In the last month, I have been this successful in living this value:

Personal Value #4: Work/Career

Instructions: If this is an area of your life that is very important to you, describe the person you would most like to be in your career or line of work. For example, some people value doing work that allows them to bring their unique talents to bear, work that allows them to express themselves, or work that ‘makes a difference’ in other people’s lives—but you should decide for yourself what kind of person you value being in your line of work.

Please write down your Work/Career values here:

Please answer the following questions by circling the number (on the right) that is true for you:

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- | | | | | |
|----------------------------|---------------------------|----------------------------|--------------------|---------------------------|
| 1. Not at all
important | 2. A little bit important | 3. Moderately
important | 4. Quite important | 5. Extremely
important |
|----------------------------|---------------------------|----------------------------|--------------------|---------------------------|
1. How important is this value to you?
 2. How committed are you to living this value?
 3. Right now, would you like to improve your progress on this value?
 4. My Fibromyalgia has impacted my ability to live this value:
 5. In the last month, I have been this successful in living this value:

Personal Value #5: Education-Schooling/Personal Growth & Development

Instructions: If this is an area of your life that is very important to you, describe the person you would most like to be with respect to your education and/or personal growth. For example, some people value qualities like being open and receptive to new ideas and perspectives or making serious and careful considerations of important issues—but you should decide for yourself what kind of person you value being with respect to your education and personal growth.

Please write down your Education-Schooling/Personal Growth & Development values here:

Please answer the following questions by circling the number (on the right) that is true for you:

- | | | | | |
|----------------------------|---------------------------|----------------------------|--------------------|---------------------------|
| 1. Not at all
important | 2. A little bit important | 3. Moderately
important | 4. Quite important | 5. Extremely
important |
|----------------------------|---------------------------|----------------------------|--------------------|---------------------------|
1. How important is this value to you?
 2. How committed are you to living this value?
 3. Right now, would you like to improve your progress on this value?
 4. My Fibromyalgia has impacted my ability to live this value:
 5. In the last month, I have been this successful in living this value:

Personal Value #6: Recreation/Leisure/Sport

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Instructions: If this is an area of your life that is very important to you, describe the person you would most like to be during recreational, leisure, and or sporting activities. For example, some people value discovering or learning new things (or spending more time with family or friends) during leisure/recreation times, or being active, competitive, and playing together as part of a sports team—but you should decide for yourself what kind of person you value being with respect to recreation, leisure, and sport.

Please write down your Recreation/Leisure values here:

Please answer the following questions by circling the number (on the right) that is true for you:

- | | | | | |
|----------------------------|---------------------------|----------------------------|--------------------|---------------------------|
| 1. Not at all
important | 2. A little bit important | 3. Moderately
important | 4. Quite important | 5. Extremely
important |
|----------------------------|---------------------------|----------------------------|--------------------|---------------------------|
1. How important is this value to you?
 2. How committed are you to living this value?
 3. Right now, would you like to improve your progress on this value?
 4. My Fibromyalgia has impacted my ability to live this value:
 5. In the last month, I have been this successful in living this value:

Personal Value #7: Spirituality/Religion

Instructions: Understand that we are not necessarily referring to organized religion in this section. If this is an area of your life that is very important to you, describe the person you would most like to be with respect to your spirituality and/or religion. For example, some people value connecting with nature and/or the people around them, connecting with God, being part of a church, and/or living out a variety of specific religious ideals-- but you should decide for yourself what kind of person you value being with respect to spirituality or religion.

Please write down your Spirituality/Religion values here:

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Please answer the following questions by circling the number (on the right) that is true for you:

- | | | | | |
|----------------------------|---------------------------|----------------------------|--------------------|---------------------------|
| 1. Not at all
important | 2. A little bit important | 3. Moderately
important | 4. Quite important | 5. Extremely
important |
|----------------------------|---------------------------|----------------------------|--------------------|---------------------------|
1. How important is this value to you?
 2. How committed are you to living this value?
 3. Right now, would you like to improve your progress on this value?
 4. My Fibromyalgia has impacted my ability to live this value:
 5. In the last month, I have been this successful in living this value:

Personal Value #8: Community/Citizenship

Instructions: If this is an area of your life that is very important to you, describe the person you would most like to be with respect to your community and your country. For example, some people value helping others in their community, advancing their political or humanitarian views at a local (or higher) political level, or helping to preserve local places of value-- but you should decide for yourself what kind of person you value being with respect to your community or role as a citizen.

Please write down your Community/Citizenship values here:

Please answer the following questions by circling the number (on the right) that is true for you:

- | | | | | |
|----------------------------|---------------------------|----------------------------|--------------------|---------------------------|
| 1. Not at all
important | 2. A little bit important | 3. Moderately
important | 4. Quite important | 5. Extremely
important |
|----------------------------|---------------------------|----------------------------|--------------------|---------------------------|
1. How important is this value to you?
 2. How committed are you to living this value?
 3. Right now, would you like to improve your progress on this value?
 4. My Fibromyalgia has impacted my ability to live this value:
 5. In the last month, I have been this successful in living this value:

VALUED LIVING AND FIBROMYALGIA

Personal Value #9: Health/Physical Well-Being

Instructions: If this is an area of your life that is very important to you, describe the person you would most like to be with respect to your personal health. For

example, some people value being active, eating healthy foods, or exercising regularly-- but you should decide for yourself what kind of person you value being with respect to your personal health and physical well-being.

Please write down your Health/Physical Well-Being values here:

Please answer the following questions by circling the number (on the right) that is true for you:

1. Not at all important 2. A little bit important 3. Moderately important 4. Quite important 5. Extremely important

1. How important is this value to you?
2. How committed are you to living this value?
3. Right now, would you like to improve your progress on this value?
4. My Fibromyalgia has impacted my ability to live this value:
5. In the last month, I have been this successful in living this value:

VALUED LIVING AND FIBROMYALGIA

Fibromyalgia Impact Questionnaire – Revised

DOMAIN 1: FUNCTION

Directions: For each of the following 9 questions, check the box that best indicates how much your Fibromyalgia made it difficult to perform each of the following activities during the past 7 days. If you did not perform a particular activity in the last 7 days, rate the difficulty for the last time you performed the activity. If you can't perform an activity, check the last box.

No difficulty 0 1 2 3 4 5 6 7 8 9 10 Very difficult

1. Brush or Comb your hair
2. Walk Continuously for 20 minutes
3. Prepare a homemade meal
4. Vacuum, Scrub or Sweep floors
5. Lift and carry a bag full of groceries
6. Climb one flight of stairs
7. Change bedsheets
8. Sit in a chair for 45 minutes
9. Shop for groceries

DOMAIN 2: OVERALL

Directions: For each of the following 2 questions, check the box that best describes the overall impact of your Fibromyalgia over the last 7 days.

Never 0 1 2 3 4 5 6 7 8 9 10 Always

1. Fibromyalgia prevented me from accomplishing goals for the week
2. I was completely overwhelmed by my Fibromyalgia symptoms

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DOMAIN 3: SYMPTOMS

Directions: For each of the following 10 questions, select the box that best indicates your intensity level of these common Fibromyalgia symptoms over the past 7 days.

No Problems 0 1 2 3 4 5 6 7 8 9 10 Severe Problems

1. Please rate the level of pain
2. Please rate your level of energy
3. Please rate your level of stiffness
4. Please rate the quality of your sleep
5. Please rate your level of depression
6. Please rate your level of memory problems
7. Please rate your level of anxiety
8. Please rate your level of tenderness to touch
9. Please rate your level of balance problems
10. Please rate your level of sensitivity to loud noises, bright lights, odors and cold

VALUED LIVING AND FIBROMYALGIA

Patient Health Questionnaire (PHQ-9)

Over the last 2 weeks, how often have you been bothered by any of the following problems?

Not at all	Several days	More than half the days	Nearly everyday
0	1	2	3

1. Little interest or pleasure in doing things
2. Feeling down, depressed or hopeless
3. Trouble falling or staying asleep, or sleeping too much
4. Feeling tired or having little energy
5. Poor appetite or overeating
6. Feeling bad about yourself – or that you are a failure or have let yourself or your family down
7. Trouble concentrating on things, such as reading the newspaper or watching television
8. Moving or speaking so slowly that other people could have noticed. Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual.
9. Thoughts you would be better off dead, or of hurting yourself

VALUED LIVING AND FIBROMYALGIA

CHRONIC PAIN ACCEPTANCE QUESTIONNAIRE

Below you will find a list of statements. Please rate the truth of each statement as it applies to you. Use the following rating scale to make your choices. For instance, if you believe a statement is 'Always True,' you would write a 6 in the blank next to that statement.

0	1	2	3	4	5	6
Never	Very	Seldom	Sometimes	Often	Almost	Always
True	Rarely	True	true	true	always	true
	True				true	

1. I am getting on with the business of living no matter what my level of pain is.
2. My life is going well, even though I have chronic pain.
3. It's OK to experience pain.
4. I would gladly sacrifice important things in my life to control this pain better.
5. It's not necessary for me to control my pain in order to handle my life well.
6. Although things have changed, I am living a normal life despite my chronic pain
7. I need to concentrate on getting rid of my pain.
8. There are many activities I do when I feel pain.
9. I lead a full life even though I have chronic pain.
10. Controlling my pain is less important than any other goals in my life.
11. My thoughts and feelings about pain must change before I can take important steps in my life.
12. Despite the pain, I am now sticking to a certain course in my life.
13. Keeping my pain level under control takes first priority whenever I'm doing something.
14. Before I can make any serious plans, I have to get some control over my pain.
15. When my pain increases, I can still take care of my responsibilities.
16. I will have better control over my life if I can control my negative thoughts about pain.
17. I avoid putting myself in situations where my pain might increase.
18. My worries and fears about what pain will do to me are true.
19. It's a great relief to realize that I don't have to change my pain to get on with life.
20. I have to struggle to do things when I have pain.

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Perceived Stress Scale

A more precise measure of personal stress can be determined by using a variety of instruments that have been designed to help measure individual stress levels. The first of these is called the Perceived Stress Scale.

The Perceived Stress Scale (PSS) is a classic stress assessment instrument. The tool, while originally developed in 1983, remains a popular choice for helping us understand how different situations affect our feelings and our perceived stress. The questions in this scale ask about your feelings and thoughts during the last month. In each case, you will be asked to indicate how often you felt or thought a certain way. Although some of the questions are similar, there are differences between them, and you should treat each one as a separate question. The best approach is to answer fairly quickly. That is, don't try to count up the number of times you felt a particular way; rather indicate the alternative that seems like a reasonable estimate.

For each question choose from the following alternatives:

Never	Almost never	Sometimes	Fairly often	Very often
0	1	2	3	4

1. In the last month, how often have you been upset because of something that happened unexpectedly?
2. In the last month, how often have you felt that you were unable to control the important things in your life?
3. In the last month, how often have you felt nervous and stressed?
4. In the last month, how often have you felt confident about your ability to handle your personal problems?
5. In the last month, how often have you felt that things were going your way?
6. In the last month, how often have you found that you could not cope with all the things that you had to do?
7. In the last month, how often have you been able to control irritations in your life?
8. In the last month, how often have you felt that you were on top of things?
9. In the last month, how often have you been angered because of things that happened that were outside of your control?
10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

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Appendix B

Table 1

Demographics for the Sample (n=134)

	Frequency	Percentage
Gender		
Female	57	42.5%
Male	77	57.5%
Age Ranges		
20-29	81	60.4%
30-39	36	26.7%
40-49	9	6.5%
50-59	6	4.4%
60-69	2	1.4%
Marital Status		
Single	37	27.6%
In dating relationship	11	8.2%
Married/Domestic Partnership	83	61.9%
Separated/Divorced	3	2.2%
Race/Ethnicity		
Asian/Pacific Islander	66	49.3%
African American	10	7.5%
Hispanic/Latino	8	6%
Native American	5	3.7%
White	45	33.6%
Mixed/Multiple race	0	0%
Employment		
Full-time	121	90.3%
Part-time	6	4.5%
Unemployed	2	1.5%
Homemaker	1	0.7%
Student	1	0.7%
Retired	1	0.7%
Unable to work/disabled	2	1.5%
Time since FM diagnosis		
Within the last year	19	14.2%
1-3 years	75	56%
4-6 years	32	23%
8-10 years	3	2.2%
10+ years	4	3%
Psychological Treatment History		
Currently seeking treatment for FM	61	45.5%
Sought treatment in Past for FM	56	41.8%
Never attended treatment	17	12.7%

Table 2

Means, Standard Deviations, and Correlations for all variables

Variable	<i>M</i>	<i>SD</i>	1	2	3	4	5	6	7
1. Activity Engagement (CPAQ-R subscale)	42.76	12.60	-						
2. Pain Willingness (CPAQ-R subscale)	35.53	9.82	.78**	-					
3. PHQ9	16.27	5.02	.76**	.65**	-				
4. FM Impact	35.37	13.83	.49**	.49**	.45**	-			
5. Stress	15.71	3.42	.67**	.67**	.61*	.39**	-		
6. Values (Question 4)	33.43	7.42	.40**	.44**	.34**	.21*	.50**	-	
7. Values (Question 5)	34.69	7.03	.34**	.24**	.28**	.04	.41**	.49*	-

VALUED LIVING AND FIBROMYALGIA

Note * $p < .05$, ** $p < .01$. Activity Engagement & Pain Willingness subscales of CPAQ-R = Chronic Pain Acceptance Questionnaire - Revised, PHQ9 = Patient Health Questionnaire 9, FM Impact = Fibromyalgia Impact Questionnaire - Revised, Stress = Perceived Stress Scale, Values (Question 4&5) = Personal Values Questionnaire - II Items 4 & 5.

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Table 3

Summary of Hierarchical Multiple Regression Analysis for value based behavior

	<i>R</i>	<i>R</i> ²	<i>SE of the Estimate</i>	<i>R</i> ² <i>change</i>	<i>b</i>	<i>SE</i>	<i>t</i>
Model 1	.21	.05	.04	.05			
FM Impact					.22	.05	2.15*
Model 2	.47	.22	.20	.18			
FM Impact					-.03	.06	-.29
Pain Willingness					.35	.11	2.36*
Activity					.16	.09	1.06
Engagement							

*p<.05, **p<.01