A historical and clinical perspective endorsing person-centered management of fibromyalgia syndrome

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Abstract

Fibromyalgia or fibromyalgia syndrome (FMS) is a complex chronic pain disorder of unknown causation frequently associated with debilitating fatigue, unrefreshing sleep, cognitive and affective symptoms. A fibromyalgia-type suffering was possibly described in the Book of Job. Analogous symptomatic conditions have been medically recognized since the early 1900s, when initially labeled as “fibrositis”. Since the early 1980s, FMS has evolved and differentiated after its characterization in a controlled study. Since then, research has focused on multiple aspects of this disorder, including characterization and management of symptoms, psychophysiology, neuroendocrine-immune pathophysiology, including central sensitization mechanisms. The complex and multifaceted nature of FMS lends itself better to a holistic (integrative medicine) or biopsychosocial approach than the more specific bioscientific pathways typical for a pathologically-defined disease.

A person-centered approach to evaluation and care more effectively addresses and encompasses the biopsychosocial aspects of this disorder than traditional bioscientific clinical methods. This review outlines a holistic multi-modal, patient-centered approach to evaluation and care as a framework for primary clinic settings. Future directions in research, diagnosis, and management of fibromyalgia patients should incorporate revised person-centered and other qualitative models of care for critical comparison to current conventional concepts and clinical practice. The more comprehensive person-centered services need to be compared to the current standardized practice in terms of their cost-effective outcomes, patient satisfaction, physician gratification, and practical logistics of providing long-term follow up and management.
Key Words: Fibromyalgia syndrome, Fibrositis, Person-centered, Biopsychosocial model, Patient-centered

1 – Introduction

Fibromyalgia or fibromyalgia syndrome (FMS) is a complex disorder with a wide-ranging symptom spectrum [1-3]. Its hallmark manifestation is generalized amplified pain which is often accompanied by debilitating fatigue, unrefreshing sleep, cognitive and affective symptoms, believed to result partly from central sensitivity processes [2-4]. The precise etiology of this disorder is yet to be elucidated, although its prominent manifestations are believed to have been recognized, since the Book of Job [5].

The term “fibrositis” was first introduced by Gowers in 1904 to describe a mixed category of symptomatic disorders [6]. Tenderness was frequently found associated with various regional pain syndromes, suggesting inflammation [6]. However, inflammation of fibrous tissue was lacking pathologically, hence the term was introduced with quotations. Within 10 years following Gowers’s description, various forms of presumed “fibrositis” and their treatments were the subject of the 1913 Harveian Society Lecture by AP Luff [7]. Dr. Luff and members of the Balneology and Climatological Section of the Royal Society of Medicine published “A Discussion on Fibrositis” in Proceedings of the Harveian Society, in 1913 (17 PubMed entries 8450-8434, 12-23-14).

Fibrositis was variously described at that time, but mainly as localized forms of chronic
rheumatism. That description differs from the modern concept of widespread body pain and
tenderness to firm palpation in specific areas of the body [1, 8]. In early descriptions, muscular
type of “rheumatism” was mainly attributed to cold, damp, and wet exposures, local injuries, and
dietary factors or disorders of the alimentary tract [7]. Gout and the “fibrositis of joints,” now
recognized properly as either osteoarthritis or rheumatoid arthritis, was excluded as a cause [7].
In that era, spa therapy, massage, and exercises were the recommended treatment of fibrositis.

2 - PubMed-indexed publications on “fibrositis” and “fibromyalgia” (Figure 1)

The 5-year numbers of articles indexed in PubMed, using the separate terms “fibrositis,”
“fibromyalgia,” and “arthritis”, are compared in Fig 1, from 1/1/1910 to 12/31/2014. The term
“fibrositis (which includes fibromyalgia)” yielded a total of 8,450 citations, which number is
slightly greater than the alternative index term of “fibromyalgia,” which yielded 8,274 citations.
Both terms were indexed considerably less frequent than “arthritis”, which yielded 131,258 entries.

The log frequency graph indicates low-level indexed citations (well under 25) of “fibrositis”
publications in each 5-year period, from 1910 until World War II (WWII, 1940-44) (Figure 1).
Then, the trend prominently increased (reaching circa 50) and remained greater for a decade.
From 1960 to 1974, the numbers of publications again decreased to a low level (under 25). The
specific term “fibromyalgia” was first indexed in PubMed in the 5-year period, from 1980-84. Of
note, the first controlled study of primary fibromyalgia was published in 1981 [1]. In the next
five years (1985-89), both the indexing of fibrositis and fibromyalgia had increased at least
three-fold or greater. The American College of Rheumatology criteria for the classification of fibromyalgia was published in 1990 [8]. Since that time (1990-1994), PubMed indexing of the specific term “fibromyalgia” steadily increased, whereas “fibrositis” steadily decreased (Figure 1).

Regarding PubMed citations of “arthritis,” less than 100 articles were indexed in each 5-year period, from 1910 until the end of WWII. Then, in the decade from 1945-54, the number of publications increased 25-fold from the preceding level (from 64 to 1,551). Since 1955, the numbers of indexed arthritis articles increased circa 30% in each 5-year period, until 2015 (from 1,551 to 30,653). Since 1990, “fibromyalgia” citations have increased about 40% in each 5-year period or even slightly more than “arthritis” (Figure 1). The sharply increased trend in numbers of indexed publications on fibromyalgia supports its significance in clinical practice.

3 – Complexity of fibromyalgia impacting clinical definition and management

Fibromyalgia is a complex and chronic multi-factorial disorder, which will be further defined in other papers of this series. For this historical review, it is characterized by widespread musculoskeletal pain accompanied by fatigue, sleep, memory and mood issues, and may be accompanied by headaches, gastrointestinal, and other somatic symptoms. Features usually accumulate gradually over time without an incriminated single triggering event, but may develop after physical trauma or psychological stress. Absence of known causation and its diverse manifestations have led to various treatments. An appreciation of comprehensive physical and
psychological support therapy is developing as well as a person-centered approach to management.

4 - Categories of treatments indexed in PubMed articles on fibromyalgia

In the total PubMed indexed articles on fibromyalgia (n=8274), treatment was a frequently addressed topic (n=4456), most often related to drug therapies (n=1429), followed by physical (n=1089), behavioral (n=920), sleep (n=764), and exercise (n=646) modalities. Less frequently mentioned therapies are the complementary and alternative medical (CAM) modalities, like acupuncture (n=140), massage (n=77), diet (n=53), and spa therapy (n=39).

Generally speaking, drug therapies are thought to influence the balance of neurochemicals and neurotransmitters that regulate symptoms, such as pain, fatigue, and mood. In contrast, non-drug modalities may more likely influence the fibromyalgia patient’s symptom complex through multifaceted pathways, including symptomatic or physical reactivities associated with the person’s condition. The evolving practice paradigm for diagnosis and management of FMS favors a person-centered and symptom-based approach using multi-modal therapies best suited to the holistic (integrative medicine) care of the individual patient [9, 10]. As part of this a multi-modal approach, drugs may be individualized to treat for pain, mood, and sleep with the goal of mitigating symptoms and restoring function [10-12]. This review emphasizes the authors’ general experiences and literature reports which support the person being the main focus of fibromyalgia management, rather than any particular alteration of behavioral, emotional, or neurophysiologic pathways.
5 - Classic medical traditions as related to fibromyalgia

Modern practice logistics in care of chronic conditions often involve multiple specialists in management of patients needing enhanced pharmacological, behavioral, cognitive, exercise, physical, and psychological therapies. The challenge is to integrate modern practice logistics, science, and humanism to improve care of individual patients affected by complex disorders.

Sir William Osler stated, “Care more particularly for the individual patient than for the special features of the disease” [13]. Dr. Francis W. Peabody advised Harvard medical school students, “One of the essential qualities of the clinician is interest in humanity, for the secret of the care of the patient is in caring for the patient” [14]. An alternative modern approach to care is to employ “precision medicine” to harness the power of genetic information and other new technology. Research is needed to determine if a fibromyalgia patient will more likely benefit from an individualized person-centered approach or a precision medicine methodology to discover and treat specific pathways in the disorder. A recent randomized controlled clinical trial investigated the comparative cost-utility of cognitive behavioral therapy (CBT) versus recommended drugs for fibromyalgia patients [15]. A stand-alone CBT intervention was somewhat more cost-effective than mainly drug therapy or usual care. Research is needed on the effectiveness and cost-effectiveness of a combined drug and CBT management [10-12], rather than either of the investigated treatments alone [15].

6 - Transitions in medical models: antiquity, bioscientific, biopsychosocial, and humanism
The physician’s role has considerably evolved over millennia to the present, from the recorded roots in teachings of Ayurveda physicians like Charaka (circa 800 BC) and Hippocrates (circa 460-377 BC) to the present. The ancient medical wisdom and tenets, codified in Charaka and Hippocratic oaths [16, 17], have guided physicians over the ages [18]. Besides such caring roles, Hippocrates expressed the reward of patient care to physicians, “Where there is love of man, there is also the love of the art” [16]. The medical value of patients’ primary data was also long-acknowledged, “It is important to ask questions of patients because with the help of these questions one will know more exactly some of the things that concern disease, and one will treat the disease better” Rufus of Ephesus, 1000 AD [19].

The post-WWII era has contributed great medical and technological advances, but a decreasing focus on the human domain [20]. The biopsychosocial model of care was developed by Dr. George Libman Engel (1913-1999), since the late 1970s [20-24]. He was a psychiatrist and medical pioneer who promoted the extension of the medical bioscience model to include scientific data on the human domain and the person’s life circumstances [20-24]. The essence of this model is to include the patient and his/her attributes as a person, a human being [21]. Physician’s preoccupation with the body and disease could neglect the scientific importance of the patient as a person [21]. Engel [21] and others [25] adapted a “systems view” of health and disease, in which the person is a central component in the organizational hierarchy of interacting and integrated social and organismic levels. Engel [21] advocates that the system level for physicians is always the person, that is the patient, whereas scientists are generally obligated to select one system level or another on which to concentrate.
Dr. Alvin R. Feinstein further reviewed scientific and humane medicine in the 21st century [26, 27]. He cautioned that statistical reductionism ignores the scope and distinctions of human illness. Randomized trials demonstrate average efficacy of therapy, not different clinical subgroups within the spectrum of disease. Individual distinctions are often crucial features of good patient care and concerns for what patients feel, think, or want should not be excluded. He questioned if the most important change now needed for clinical medicine is a new paradigm that restores patients to the center of the clinical universe [27]. Further, he indicated that an additional “basic” humanistic science can be developed for the interventions of patient care [26].

7 - Holistic concepts of health and disease

The broader concept and framework of human illnesses encouraged a holistic view of medicine (also called wholistic, humanistic, alternative, and consciousness medicine), which has invited numerous professionals and practitioners, besides physicians [28-30]. The preceding literature supports the importance of person-centered care, especially in a multi-symptomatic condition, as fibromyalgia, in which traditional therapies have had limited efficacy [15, 31]. The scientific challenge is to deal with patients as whole people in their clinical evaluation and care.

A central principle of the holistic concept is that the individual – not the medical care system, not society – is responsible for the development and maintenance of health [32]. Arnold S. Relman, Editor of The New England Journal of Medicine, commented on holistic medicine and the first annual session of the American Holistic Medicine Association (AHMA), held in May 1978 [30]. Dr. Relman asked [30], “Doesn’t every experienced physician know that he must deal with
patients and not just their diseases?” He argued that the traditional views of holistic medicine are part of the traditions of medicine. He objected, however, to a long listing of organized systems of health practices outside the mainstream of Western medicine and cautioned against an abandonment of science in “holistic medicine” [30]. James S. Gordon, a research psychiatrist, reviewed advances and shortcomings of holistic medicine [33]. He endorsed a combination of health promotion and public education to enhance individuals’ wellness as well as incorporating controlled and replicated studies to determine effectiveness of particular diagnostic and therapeutic techniques of this alternative practice approach [33].

8 - Holistic concept of health and illness and the biopsychosocial model

An holistic concept of fibromyalgia has personally (ATM) evolved over a five decades clinical-epidemiology career [34] and over three decades collaboration in studies of fibromyalgia [1, 35]. The classic epidemiological model of agent, host, and environment has proved valuable in deriving a holistic concept of health and illness [29]). A concept of personalized medicine is an extension of the past century’s dominant bioscience or biomedical model [20]. The word ‘health’ is derived from an Anglo-Saxon word ‘hal’ meaning whole and ‘heal’, which comes from the same root as ‘holy’ [29]. Consequences of adverse personal, social, and environmental factors on health have been noted since ancient times [36].

Although, clinical and research advantages of the biopsychosocial model in understanding chronic illnesses have been carefully elucidated [20-24], real-life practice logistics have limited its widespread evolution and acceptance. Accordingly, the doctor-patient relationship has not
prospered over the past decades. Personalized multidisciplinary symptom management programs demonstrate benefits in FMS [37, 38], but are not widely available. Thus, such model is not customarily employed for disorders like fibromyalgia, which have multiple subjective symptoms as pain, stiffness, anxiety, sadness, fatigue, dysfunction, and other particular complaints. In primary care, personalized complaints are often managed with separate prescriptions, rather than the provider interacting and guiding management specific to the person’s symptoms and life circumstances [9, 39, 40].

9 – Essential components of the doctor-patient relationship

The doctor-patient relationship has been the continuous core component, if not the historical basis, of medicine and therapy, including Ayurvedic traditions [17] and Hippocratic teachings [41]. The still-needed emphasis on an individual person’s conditions has considerably diminished, since the earlier 20th century by the increasing wave of scientific advances in medical diagnoses and therapy [42]. Defining the patient-physician relationship for the 21st century is a priority issue in disease management, professional therapists’ responsibility, and education [43-45].

A good patient-physician relationship is considered “the very heart of healthcare delivery” as it can improve access to care and promote healing [45]. A consensus report on patient-physician relationship indicated 7 principal elements, including: (1) patient self-assessments, (2) access to care, (3) personalizing care, (4) professional education and self-care, (5) integration of information, (6) patient’s role in decision-making, and (7) patient-centered and physician-
centered outcomes [45]. Favorable patient-centered outcomes included minimizing the disease impact on one’s life and the ability to effectively self-manage with confidence. Favorable physician-centered outcomes included the gratification in sharing in the patients satisfying outcome.

Nearly 3 decades ago, a population-based model was proposed of a biological gradient of clinical and subclinical FMS features (iceberg phenomenon) [35]. It considered the varied degrees and frequencies of manifestations in the population, ranging from the most prominent involvements in a minority of persons (tip of the iceberg), to the lesser features which occur frequently in the populace. The majority of persons with minor manifestations may not receive medical diagnosis or attention [35]. Given the varied and personalized features of persons with fibromyalgia, an individualized model of evaluation, care, and management approach to this condition was intuitively promoted [9, 35].

10 - Chronic Care Model (CCM) and Personalized Health Care (PHC) activities

Chronic disease differs from acute episodic disease which may be cured, allowing the patient to return to normal. Chronic disease is continuous, rarely cured, and the patient can live long lives with symptoms from the disease or their behavioral, emotional, and functional consequences [46]. Like primary FMS, “Chronic disease requires a practice of medicine quite different from that used for acute disease,” as contrasted by Dr. Halsted Holman [46]. Continuity and integration of care are essential, as is a healing physician-patient relationship in which the patient inevitably becomes a principal caretaker. The patient and physician partnership bring
complementary knowledge and reciprocal responsibilities to the care process. An ambulatory chronic care model (CCM) has been formulated, including essential elements of patient and physician roles and integration of education in the process, along with other care resources [46, 47], as well as a focus on outcomes research effectiveness [48].

Personalized health care (PCH), including the CCM, is recognized as a potential approach to improve cost-effectiveness in management of a number of chronic diseases, including diabetes, chronic obstructive pulmonary disease, cardiovascular diseases, including chronic heart failure [49, 50], and rheumatoid arthritis [51]. Further research is encouraged on the elements of such models to improve care, including delivery system design, self-management support, clinical information systems, decision support, and health system organization. The goal is to enhance patient self-management, desirable behavioral changes, and therapeutic decisions favoring disease management [46-51].

11 - Conceptual framework of person-centered management of FMS

Person-centered management of FMS is analogous to a (w)holistic approach to health, both of which broaden the conceptual and therapeutic boundaries as well as understanding limits of the medical model [29, 33, 35]. Health and well-being are also influenced by circumstances or factors outside the medical therapy realm, like socioeconomic status, behavioral and environmental circumstances, and ways of living. All of the preceding factors affect body, mind, and emotional reactivity [52].
Alterations of particular pain processing pathways have been reported in fibromyalgia patients by brain functional magnetic resonance imaging [53]. However, no clear mechanism has been identified to explain the diverse degrees of manifestations which characterize individual FMS patients. In complex disorders like FMS, effective communication between the medical provider and suffering person can encourage greater understanding of the multiple body symptoms and their related behavioral and emotional impacts. Effective communications can also aid patient education, which supports self-management activities. A broader management framework of the person suffering with FMS can help to understand and integrate the multiple symptoms and dysfunctions. Currently, those alterations are not easily translated or well understood solely by traditional bioscientific approaches, nor specifically treated by drugs.

In a personalized approach, non-pharmacological and self-management strategies are combined with the individual’s needed pharmacological interventions, to further support healing or recovery processes. Multi-modal management is often needed to diminish diverse symptoms, including pain, non-restorative sleep, easy fatigue, and emotional or psychological manifestations.

12 - Person-centered and patient-centered approaches in care

Person-centered therapy (PCT) had its origin in the humanistic school of psychotherapies developed by Carl Rogers [54-56]. The therapist’s three interrelated core qualifications essential in promoting PCT relations are: (1) willingness to openly relate to clients; (2) convey unconditional positive regard, and (3) achieve an empathetic understanding of the client’s
perspective. The aim is to provide clients with a sense of self and personal realization of their attitudes, feelings, and behaviors. Such approach can help develop patient’s motivation in self-management to the degree practically achievable in the person’s circumstances. The person-centered therapy approach focuses on individual patient’s expressing their true feelings without fear of judgment and discovering those issues most relevant to their personal symptomatology and reactivities.

Patient-centered care supports active involvement of patients and their families in care models and decision-making about individual options for management [57]. Patient-centered care includes five attributes: (1) focus on the “whole-person”; (2) coordination and communication; (3) patient support and empowerment; (4) ready access, and (5) autonomy at every level of care. This model also encourages patient involvement in self-care. The patient-centered model primarily addresses procedural logistics of care.

13 – Rationale for a person-centered approach to FMS

Although standard care in FMS has demonstrated some efficacy [31, 58], lack of understanding of the precise mechanisms that contribute to FMS and the absence of specific biomarkers or brain scan make both conceptualization and systematic assessment of the illness challenging for the health care provider. Such ambiguity can also diminish validity of the patient’s illness in health care settings [59]. Because pain and fatigue cannot be objectively visualized, like joint swelling or auscultated like a murmur, their assessment at the current time is based solely on patient self-report. Notably, the assessment of patient-reported symptoms in brief clinical
encounters is not as simple as may be supposed. Scant research has been reported on outcomes of person-focused care of FMS patients [9].

*Reasons for the clinical challenge of validating FMS*

*First*, the patient may have endured several years of suffering related to the illness before seeking medical attention [60]. Due to the chronic nature of this illness, persons may have developed maladaptive coping strategies in response to daily suffering, for instance catastrophizing [61]. Maladaptive coping behaviors can contribute to difficulties in patient interactions. Adequate time to validate the person’s symptoms and effective patient education is needed to address such challenges. Doing so can facilitate personal empowerment and encourage active self-management.

*Second*, similar to other chronic conditions, cross-sectional assessments at one or two time points are generally not adequate to properly understand the variability and interrelation of symptoms in fibromyalgia and their relationship to medical and psychiatric comorbidities present in the person. Rather, longitudinal clinical assessment over weeks or months may be needed for appreciation and conceptualization of a person’s unique symptom complex. Several studies have demonstrated that symptoms of fibromyalgia have considerable daily variability and fluctuations over time trends [62-64]. Symptoms of fibromyalgia can vary by upwards of 10-15% from day to day [64]. Lack of consideration of such patient variability in research and clinical settings may be one factor why evaluation of current efficacy of fibromyalgia care is largely inconclusive.
Longitudinal clinical assessment promises to facilitate a clearer understanding of an individual’s symptom pattern. Such research can guide personalization of symptom management.

Third, researchers have demonstrated subgroups of symptom combinations in heterogeneous samples of patients with fibromyalgia [65-70]. Variables responsible for subgrouping in these studies include: symptom severity; sociodemographic, physiological, and psychophysiological factors; comorbidities, and psychosocial functioning. Vincent et al. [70] identified and confirmed four subgroups within two independent samples of fibromyalgia patients: 1) low levels of all symptoms (pain, fatigue, sleep, function, stiffness, cognition, depression, and anxiety); 2) moderate symptom levels with low anxiety and depression; 3) moderate symptom levels with high anxiety and depression, and 4) high levels of all symptoms. Mood was the most important factor contributing to the subgrouping in the report by Vincent et al [70], similar to two other studies [65, 67]. However, symptom severity and comorbidities contributed most to the subgrouping in another study [71]. Knowledge of patient subgroups is important, since persons with FMS belonging to different subgroups (clusters) may respond dissimilarly to symptom management programs and pain rehabilitation [72, 73]. Hence, serial assessment of a person’s symptom subgroup (cluster) could guide person-centered fibromyalgia care.

Fourth, fibromyalgia patients often have one or more associated chronic conditions that can also impact their complaints. A recent study by Vincent et al [74] demonstrated that over 50% of a community cohort of fibromyalgia patients had seven or more chronic conditions. The most frequent co-morbidities were other pain disorders (chronic joint pain/degenerative arthritis and migraines/chronic headaches), depression, and anxiety. Additionally, over 50% of the cohort met
criteria for metabolic syndrome. The presence of fibromyalgia alone is a coping challenge for individual patients, but the symptom burden is greatly amplified when the condition is compounded by psychological and medical comorbidities. Although concurrent assessment and management of comorbidities adds to the complexity of a clinical encounter, it is important in person-centered fibromyalgia care.

Fifth, polypharmacy is commonly reported in fibromyalgia patients and frequently complicates assessment of the clinical pattern. In the study by Vincent et al. [74], greater than 40% of the community cohort were prescribed three or more medications for fibromyalgia, and greater than 10% were prescribed 5 or more medications. Additionally, 22% of the cohort were prescribed at least one opioid, despite the lack of definitive data supporting such use in fibromyalgia. Approximately 19% of the cohorts were prescribed benzodiazepines. Although some of these medications may offer symptomatic benefits, adverse effects could contribute to comorbidity.

In summary, the challenge of validation and effective fibromyalgia management is hampered by: 1) chronic nature of the symptoms; 2) psychophysiological burden; 3) complex concurrent presentation of multiple symptoms over time; 4) multiple associated comorbidities, and 5) often polypharmacy, which should optimally be considered when designing a person-centered approach (Figure 2).

14 - Pragmatic person-centered considerations in management of fibromyalgia (Figure 2)
At this time, a systematic symptom- and person- based assessment has not been reported in fibromyalgia care, although such approach has been critically evaluated [9]. Components to be considered in pragmatic person-centered fibromyalgia care include: 1) effective and empathetic communication; 2) validation of a person’s suffering; 3) identification and serial assessment of an individual’s symptom profile; 4) concurrent assessment of comorbidities and other clinical factors; 5) education to enhance a person’s knowledge about the illness and the role of self-management; 6) provision of individualized pharmacological and non-pharmacological therapies; 7) non-judgmental support of patient participation in self-management, and 8) periodic motivational electronic or telephone follow-up to support adherence. If these services are distributed by appropriate members of the health care team and can be demonstrated to be effective, they could also be designed to be delivered in a cost-effective manner.

Several validated questionnaires can be used to help evaluate commonly occurring symptoms [75, 76]. Examples of these questionnaires were recently reviewed [70] and include: 1) the Brief Pain Inventory (pain); 2) Multidimensional Fatigue Inventory (fatigue); 3) Medical Outcomes Sleep Scale (sleep); 4) Beck Depression Inventory (depression); 5) Hospital Anxiety and Depression Scale (anxiety and depression), and 6) the Fibromyalgia Impact Questionnaire (individual symptoms and overall disease severity). Judicious use of such questionnaires in clinical settings may assist in characterizing a person’s symptom spectrum and its longitudinal assessment, thereby enhancing the physician’s personalized qualitative evaluation [70].

By identifying a person’s key symptoms, medication or non-pharmacological strategies could be tailored more particularly to the individual’s profile. Person-centered management, based on individualized symptom patterns offers expected advantages over current ad hoc protocol
approach. Based on the subgroups identified by Vincent et al. [70], a clinician may consider initial management with non-pharmacological therapies if a person’s symptom profile belonged in Cluster 1 (comprised of persons who scored comparatively low on all symptoms). These modalities may include cognitive-behavioral techniques, exercise, and physical therapies, and importantly, education for self-management of symptoms. If treatment response is inadequate, pharmacological agents could be added to supplement the therapeutic program.

To the contrary, if a person’s symptom profile belongs in Cluster 4 (persons who scored high on all symptom domains), the clinician might expedite participation in an intensive pain rehabilitation program as a more effective management strategy for persons with particularly challenging symptoms. In this more advanced patient population, standardized outpatient treatment options are frequently ineffective.

In a middle course, if a person’s scores belong in Cluster 2 (comprised of persons who scored comparatively high on fatigue, sleep, pain, dysfunction and stiffness, but low on cognitive symptoms, anxiety, and depression), initiating a medication that benefits both pain and sleep, such as a tricyclic antidepressant or alpha-2 delta ligand, along with non-pharmacological treatment, might be an early approach to management in an outpatient setting.

Alternatively, if a person’s scores belong in Cluster 3 (comprised of persons with moderate scores on fatigue, sleep, pain, function, and stiffness, but high on cognitive symptoms, anxiety, and depression), a clinician may want to start by addressing depression and anxiety. An example of possible treatments for this subgroup includes serotonin-norepinephrine reuptake inhibitors
(e.g. duloxetine, milnacipran, or venlafaxine) or tricyclic antidepressants (e.g. amitriptyline and nortriptyline) along with non-pharmacological symptom management modalities. Once pain and depression have been adequately addressed, additional pharmacotherapy and behavioral modalities could be considered to improve sleep.

15 - The Mayo Clinic Fibromyalgia Treatment Program: (Figure 3)

A formalized consultative person-centered, multidisciplinary fibromyalgia treatment program has been developed at Mayo Clinic [38]. It particularly emphasizes education and self-management of fibromyalgia. The program begins with a nursing assessment, during which individuals have the opportunity to share their personalized story and have their illness experience validated. Then, patients meet with a medical provider for a thorough symptom assessment, evaluation of comorbidities and medication recommendations, including assessment of polypharmacy. Subsequently, patients meet with an exercise coach to assess current health behavior, motivation for change, level of daily exercise and to establish goals for personal health and exercise. Afterwards, a two-day program includes interactive CBT-based education sessions focused on understanding fibromyalgia, central sensitization, the cycle of chronic pain, and self-management activities (Figure 3).

Most sessions are delivered by registered nurses with content expertise in fibromyalgia. Family members are encouraged to attend all components of the program and receive instruction on how to help their family member implement self-management strategies. Following completion of the program, individuals are encouraged to work with their primary care provider to incorporate
consultative recommendations, create local support teams to maintain their care, and allow for continued evaluation and modification of recommendations, if needed. Additional recommended care may include psychiatry and psychological services, physical therapy, personalized exercise, biofeedback, pool-based activities, acupuncture, massage, and other modalities. Components of such model can be delivered in primary care settings by utilizing a team approach and use of web-based learning, as has been demonstrated [77].

16 – Future Directions

At the current time, although the management of FMS in primary care settings may be a difficult challenge, the problem is real and here to stay. Further, with the growing epidemic of chronic pain in the United States, fibromyalgia may also increase in the population. Hence, it is important to create accessible, primary care based, integrated, and coordinated models to provide effective person-centered fibromyalgia services. Such models exist for other chronic conditions, such as congestive heart failure, diabetes, asthma, and depression and evidently improve both patient care and clinical outcomes [50, 78, 79]. For example, integrated behavioral health care now exists in many parts of the country [78, 79]. Such collaborative models include primary care providers, behavioral health specialists, and community-based care coordinators, who work towards improvement in mental health. Such models have benefitted patients with mental health status by providing improved access to needed services through primary care settings, facilitating communication between providers, and ongoing monitoring and assistance with self-management.
A similar collaborative model can be employed by the primary care physician or rheumatologist for person-centered fibromyalgia management that includes consulting pain experts, behavioral health specialists, and integrative medicine professionals. By use of a collaborative model, complex patient care can be extended from a primary care physician or rheumatologist alone to a collaborative team, while maintaining a focus on the “whole–person”, including the patient’s needs, preferences, and central priorities. Notably, the person-centered care model need not be established in a first consultation visit nor even in a few subsequent visits. Rather, the primary goal is for the physician to establish a mutually-supportive doctor-patient relation in those early visits. Then, depending on the circumstances and complexity of the clinical problem, the many aspects of the disorder can be addressed with collaborating team professionals over the next months, if not years. In view of the high frequency of self-reported depression in fibromyalgia patients (circa one-third), besides anxiety and other emotional stresses [80], it is important for the primary provider to help the patient understand and cope with their reactions and condition.

The rationale and justifications for person-centered care of FMS likely applies to other chronic, complex, and heterogeneous conditions with recognized subgroups, but cannot be critically addressed in this review. This model deserves attention and study in such other chronic diseases, including arthritis, obesity, and cancer. Those conditions also share clinical features with FMS, given their heterogeneous rather than homogenous presentations as well as the occurrence of chronic symptoms, such as fatigue, affective features, and pain.

This review considers the logistical realities of the primary practitioner or rheumatologist, and is intended to outline the desired scope of FMS management, rather than to direct particular procedural protocols. Person-centered care of the fibromyalgia patient deserves further critical
and controlled studies to evaluate and compare this model with the standard practice procedures on quality of care, cost-effectiveness, patient satisfaction, physician gratification, and practical logistics of providing long-term effective management.
Conflict of Interest

No conflict of interest in this review.

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References


Running Head: Person-centered management of fibromyalgia

Legend of Figures

Figure 1. Log frequency trends of PubMed-indexed “fibrositis”, “fibromyalgia” and “arthritis” labels by 5-year intervals.

Figure 2. Multi-modal patient-centered fibromyalgia patient evaluation and care

Five-Year Interval Log Frequencies of PubMed Indexed Fibrositis/Fibromyalgia Categories and Arthritis Articles
### Figure 2. Multi-modal patient centered fibromyalgia evaluation and care*

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<tr>
<td>- Treatable pain generators?</td>
<td>PT, acupuncture, or tender point injections</td>
</tr>
<tr>
<td><strong>Fatigue:</strong></td>
<td></td>
</tr>
<tr>
<td>- Severity?</td>
<td>Education in pacing and energy conservation</td>
</tr>
<tr>
<td>- Primary medical causes of fatigue?</td>
<td>Treat medical causes of fatigue</td>
</tr>
<tr>
<td>- Other</td>
<td>Slow, graded exercises to improve energy</td>
</tr>
<tr>
<td><strong>Sleep:</strong></td>
<td></td>
</tr>
<tr>
<td>- Severity?</td>
<td>Pharmacotherapy guided by symptoms</td>
</tr>
<tr>
<td>- OSA, RLS, PLMD, and other sleep disorders†</td>
<td>Sleep medicine referral for treatable disorders</td>
</tr>
<tr>
<td>- Other</td>
<td>CBT for unrefreshing sleep</td>
</tr>
<tr>
<td><strong>Cognition:</strong></td>
<td></td>
</tr>
<tr>
<td>- Severity?</td>
<td>Severity may require subspecialty referral</td>
</tr>
<tr>
<td>- May need neuropsychological evaluation?</td>
<td>Evaluation may require subspecialty referral</td>
</tr>
<tr>
<td><strong>Mood or Anxiety:</strong></td>
<td></td>
</tr>
<tr>
<td>- Severity of various psychological disorders?</td>
<td>Pharmacotherapy guided by mood disorders</td>
</tr>
<tr>
<td>- Screen for personality disorders</td>
<td>Subspecialty referral for inadequate responses</td>
</tr>
<tr>
<td>- Assess self-efficacy</td>
<td>CBT to help drug therapy and enhance self-efficacy</td>
</tr>
<tr>
<td><strong>Physical Factors:</strong></td>
<td></td>
</tr>
<tr>
<td>- Evaluate comorbid medical disorders</td>
<td>Address weight management and other conditions</td>
</tr>
<tr>
<td>- Assess status of conditioning</td>
<td>Exercise program may be needed for conditioning</td>
</tr>
<tr>
<td>- Assess for polypharmacy</td>
<td>Address and manage polypharmacy</td>
</tr>
<tr>
<td><strong>Socioeconomic:</strong></td>
<td></td>
</tr>
<tr>
<td>- Assess social support</td>
<td>Provide resources, as patient support groups</td>
</tr>
<tr>
<td>- Screen for abuse</td>
<td>Appropriate referral may be needed for abuse</td>
</tr>
<tr>
<td>- Screen for domestic violence</td>
<td>Referral may be needed for domestic violence</td>
</tr>
</tbody>
</table>

*Primary providers may be able to assume most of the supports, but specialty referral may also be needed. †Obstructive sleep apnea (OSA), Restless leg syndrome (RLS), Periodic limb movement disorder (PLMD)
Running Head: Person-centered management of fibromyalgia

Figure 3 (Masi and Vincent Paper)

<table>
<thead>
<tr>
<th>Day</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Hour RN Visit</td>
<td>Introduction to Fibromyalgia</td>
<td>Experiential: Graded Exercise</td>
<td>Experiential: Stretching</td>
<td>Education of Family Members</td>
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<tr>
<td>90 Minute Fibromyalgia Provider Visit</td>
<td>Central Sensitization</td>
<td>Experiential: Paced Breathing</td>
<td>Medication Management</td>
<td>Question and Answer Session</td>
<td></td>
</tr>
<tr>
<td>Consult with Exercise and Endurance Coach</td>
<td>Cycle of Pain</td>
<td>Relaxation Response</td>
<td>Experiential: Time Management Strategies</td>
<td>Wrap-Up with MD</td>
<td></td>
</tr>
<tr>
<td>Additional Subspecialty Consults as Indicated</td>
<td>Adopting a Neutral Approach</td>
<td>Experiential: Guided Imagery</td>
<td>Moderation</td>
<td>Wrap-Up with Exercise and Endurance Coach</td>
<td></td>
</tr>
<tr>
<td>Additional Subspecialty Consults as Indicated</td>
<td>Positive Psychology in Pain Management</td>
<td>Physiology of Stress</td>
<td>Medical Impact of Forgiveness</td>
<td>Experiential: Biofeedback</td>
<td></td>
</tr>
</tbody>
</table>

Initial Consults  Self-Management Training  Wrap-Up