

How to improve therapeutic encounters between patients with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome and Health Care Practitioners

Eleanor Stein MD, FRCP(C)
Psychiatrist in Private Practice and
Clinical Assistant Professor, Department of Psychiatry, University of Calgary
Calgary, Alberta Canada
Email: espc@eleanorsteinmd.ca

Eva Stormorken RN, CRNA, MNSc, PhD Candidate
Independent Contractor, Norway
Email: Eva.Stormorken@online.no

Bengt Karlsson RN, Family Therapist, Dr. Polit - Professor in mental health care at
Buskerud University College, Faculty of Health Sciences, Norway
Email: Bengt.Karlsson@hibu.no

Abstract

Background: Clinical practice and the medical literature abound with reports of mutual dissatisfaction between individuals with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and health care practitioners.

Purpose: In this paper we: 1) formulate and describe the common therapeutic challenges in the care of patients with ME/CFS and 2) present a patient-centered, collaborative practice model that may mitigate these challenges.

Method: We have combined clinical experience with hundreds of patients, a thorough review of the medical and psychotherapy literature and comments from patients and colleagues to arrive at our proposed practice model.

Findings and Discussion:

We have identified six common therapeutic challenges listed below. From our experience and the psychotherapy literature we have identified a relatively simple patient-centered intervention for each therapeutic challenge. These interventions are recommended for health care practitioners who find themselves in difficulty while working with patients with ME/CFS.

1. Disagreement about the validity and severity of ME/CFS - Validate the patient's experience and openly discuss differences of opinion.
2. Disagreement about the etiology and best management of ME/CFS – Find and validate the truth in the patient's position.
3. Frustration due to lack of improvement - Collaboratively search for hope.
4. Altered power balance between practitioner and patient - Clarify and increase practitioner expertise.
5. Working with patients who feel unheard - Listen to the whole story.
6. Gap between needed and available services - Build a coalition to access needed services.

Conclusions: Therapeutic relationships with patients with ME/CFS can be rewarding and enjoyable. The interventions highlighted in this paper may assist practitioners who feel otherwise.

Key Words: Chronic Fatigue Syndrome, collaborative practice, health care practitioners, Myalgic Encephalomyelitis, patient-centered therapy, therapeutic relationships

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Background

The first and second authors' clinical experience with hundreds of patients over more than a decade repeatedly shows that there are frequent strains and misunderstandings between patients with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) [1] and health care practitioners. The medical and social science literature confirms that this observation is not limited to our practices. Problems in the therapeutic relationships of ME/CFS patients and their health care practitioners are consistently reported [2-10]. The lack of a gold standard diagnostic test for ME/CFS leaves the door open for practitioners to doubt that ME/CFS exists or that it is a serious condition [2-4, 10-15]. A polarized debate about the relative roles of the mind and the body has emerged [16, 17]. At the core of the debate is lack of knowledge about the precise mechanism of ME/CFS, making it a contested condition [6, 7, 11, 18-20].

Health care practitioners lack education about ME/CFS [7, 21]. As a result many practitioners are not confident in making a diagnosis of ME/CFS [3, 10, 12] and very few use accepted criteria to diagnose the condition [14, 15, 20]. Some practitioners [6, 11] attribute negative personality characteristics to their ME/CFS patients rather than acknowledging their own lack of knowledge. Many view their patients with ME/CFS as time consuming and burdensome [6, 10, 22]. This forms the context for misunderstanding that can impede effective therapeutic collaboration [7].

Within medicine, ME/CFS has no specialty home. Patients are often sent to multiple specialists who rule out various conditions within their specialty but do not offer an integrated approach to management. As a result the leadership that often comes from specialists is lacking.

There is an increased acknowledgement "that the problem is the medical encounter, the interaction between the doctor and the patient, and not just the patient themselves" [p.267] [7]. The field of psychotherapy research is in transition from the theory of specific treatment "packages" to identifying which therapeutic factors and responses impact outcomes in real life settings [23, 24]. This is the field of practice-based evidence and patient-focused research [25]. Norcross & Lambert state that "...the best available research clearly supports the healing qualities of the therapy relationship and the beneficial value of adapting that relationship to the patient characteristics beyond diagnosis" [p.4][26].

Collaborative practice theory highlights that the fundamental ideas about collaboration have applicability across a variety of human systems and are independent of the clinical model chosen (e.g. biomedical, psychotherapeutic) [27-29]. Anderson uses the phenomenological term "being with" in therapeutic relations to describe a posture, an attitude and a tone that communicates to another the special importance that she or he holds [29-31]. With this in mind, we propose a practice model that is grounded in patient-centered care and collaborative practice. Our hypothesis is that true collaboration may mitigate the polarization, misunderstandings and impasses that often arise in the management of ME/CFS.

Collaborative interactions include: reflective listening [32], obtaining shared understanding [33], building trust [34], and employing shared decision making [33, 35].

Purpose

1) To formulate and describe the common therapeutic challenges that arise in the care of patients with ME/CFS and 2) To present a patient-centered, collaborative practice model that addresses these challenges.

Method

The first author (E. Stein) has run a private psychiatric practice for patients with ME/CFS and related disorders since 2001. In the course of assessment and treatment, individually and in groups, many patients have disclosed the difficulties they have experienced with other health care professionals; difficulties that often led to failure to progress and sometimes termination of the therapeutic relationship. The proposed hypotheses were developed from the author's clinical experience and the suggested therapeutic approaches have been used in her practice.

The second author (E. Stormorken), an expert nurse, has since 2004 facilitated management groups for patients with ME/CFS in two different specialist services, university and county hospital settings. This author undertook a literature review in spring 2012 to identify issues pertaining to the patient-practitioner interaction in ME/CFS. The search terms used in AMED; CINAHL; Medline and PsycInfo were: Chronic Fatigue Syndrome, Myalgic Encephalomyelitis, professional-patient relationship, nurse-patient, doctor-patient, physician-patient, patient-centered communication, clinical encounter, medical encounter, collaborative care/practice, shared decision making, patient-centered communication and therapeutic alliance.

The third author (B. Karlsson), a family therapist and academic, introduced us to "practice based evidence", a model in which patient experience is considered a valid and useful resource to improve collaborative, clinical care [36, 37].

Patient perspectives have been integrated with research evidence and clinical knowledge to arrive at the proposed practice model.

A Proposed Practice Model (Findings and Discussion)

Based on the literature review and extensive clinical experience, six therapeutic challenges are found to be common in the management of patients with ME/CFS. Each of these is directly related to the status of ME/CFS as a contested condition. The challenges are: 1. Disagreement about illness validity, 2. Disagreement about etiology and best treatment, 3. Frustration due to lack of improvement, 4. A shift in power in the therapeutic relationship, 5. Patients who feel unheard and 6. Inability to access needed services. Using a patient-centered and collaborative framework, we propose practical interventions for practitioners to address each of these challenges.

In this section each challenge is discussed in some detail and is then followed by a proposed intervention. The proposed interventions are independent of practitioners' personal beliefs about the etiology and best management of ME/CFS. As a result they may be utilized by practitioners of all disciplines including physicians and allied health professionals and of all belief systems across the bio-psycho-social spectrum.

We are addressing in this paper the challenges that arise in therapeutic relationships not in treatment protocols.

Challenge 1: Disagreement about illness validity and severity

Doubts about the validity of ME/CFS arise for several reasons including the lack of a sensitive and specific biomarker and the condition not fitting into any previously known bio-medical paradigm. This problem will be alleviated as diagnostic tests are developed. However, in the meantime, when a health care practitioner doubts the existence or severity of a patient's symptoms secondary problems develop [38, 39]. Patients may respond by bringing large amounts of information to an appointment to support their claims or by seeing several practitioners until they find one who "believes" them [9, 35]. Practitioners may misinterpret this iatrogenic behavior as evidence of pre-existing personality pathology and over concern with health [6, 11, 19].

Intervention 1: Validate and discuss differences of opinion

The first necessity in a therapeutic relationship is the development of rapport and trust [34]. This requires an open mind on the part of practitioners and the ability to listen to and validate patients' experiences regardless of personal beliefs. If a practitioner contradicts a patient's views before trust has developed, the patient is likely to react defensively and become entrenched in his/her position. Further attempts by the practitioner to introduce alternative views will be futile. Therefore practitioners should start by listening to and empathizing with patient's experience, even if they do not understand or agree with some of the symptoms or assumptions. By repeating back to the patient the salient points of the history and the associated feelings, the practitioner can confirm understanding of the patient's point of view [40].

Once the patient feels understood, and not sooner, the practitioner's opinions should be made known with transparency. This can be done through verbal feedback and/or by giving the patient a copy of the consultation letter/opinion to read and asking for feedback [41]. The goal of this exercise is to correct errors, glean further information from the patient and to identify areas of differing opinion. It also furthers dialogue. This early feedback strategy differs from the traditional medical model and is an example of patient-centered consultation [40]. Frank discussion about differences in opinion is the first step to developing a mutually acceptable understanding [34].

Challenge 2: Disagreement about etiology and best management of ME/CFS

Conflict can arise if practitioners recognize the presence and severity of a patient's condition but differ from the patient in beliefs about the etiology and best management of the condition [7, 18, 39]. In ME/CFS an unfortunate polarization has developed between those who espouse a primarily bio-medical etiology and management and others who posit a primarily psychological model [16, 17, 42]. According to Jason "few other illnesses have had such antagonism between these opposing 'psychological' versus 'biological views" [p.309][43].

Intervention 2: Validate the patient's position

With another condition beset by polarized views, Borderline Personality Disorder, the most widely used treatment is Dialectical Behavior Therapy (DBT) [44]. In DBT therapy "validation strategies are absolutely essential" [p.45][45]. Validation occurs through use of "a non-judgmental clinical attitude and a continual search for the

essential validity of each client's response"[p.45][45] [46]. Experience shows that recognizing the essential validity of both poles of the etiological and management debate in ME/CFS (e.g. bio-medical vs. psychological) and striving for a synthesis can be successful.

During the process of arriving at a synthesis/consensus, it is invaluable to admit that even very experienced and authoritative individuals have different opinions about ME/CFS [47, 48]. It is also helpful to acknowledge that in both health and illness, the mind and the body constantly interact at the molecular level. It is impossible to differentiate between the effects of the body on the mind and the effects of the mind on the body. Practitioners and patients can collaborate to identify together all of the biological, psychological, social and spiritual factors that affect an individual patient's health and then focus on those factors which can be most easily changed.

Challenge 3: Frustration due to lack of symptom improvement

There is no consistently effective treatment for ME/CFS. In natural history studies, less than 10% of patients recover [49]. This means that many patients fail to improve despite the best efforts of all involved. Practitioners are prone to feel incompetent and frustrated if patients do not improve [50]. It is frustrating for both patients and practitioners when patients fail to tolerate even modest interventions of medications, exercise or psychotherapy or are too ill to actively participate in treatment at all as is common in those who are severely affected with ME/CFS. If initial management suggestions do not lead to improvement, patients may wonder whether their quality of life will ever improve and they become at risk of despair or depression. Practitioners may believe that patients who are not getting better are not trying hard enough or are not following recommendations and blame the patient for the lack of progress: another dialectic/polarity to be synthesized [11, 19].

Intervention 3: Collaborate in a search for hope

The contextual issue here is lack of knowledge [2, 15, 51]. If this reality is discussed transparently, then blame and frustration can be directed at the complexity of the condition and the lack of clear direction rather than at each other. Patients and practitioners can work collaboratively to increase knowledge and find glimmers of hope [26]. The search for hope is a process [52, 53]. Hope is not achieved once and for all, but waxes and wanes with symptom fluctuations.

Advocacy groups can play a role in maintenance of hope. They may offer much needed information and support which is not otherwise available [54, 55]. Patients benefit from knowing that others have struggled with similar problems i.e. that they are not alone. As with all interventions, peer support also has risks. Reading or hearing about others' struggles may be overwhelming if not balanced with discussion of learning or coping [56]. Knowing that one's medical practitioner will not give up hope even if one is the "most challenging case" is invaluable to patients.

Challenge 4: The altered power balance between patient and practitioner

The balance of power in a therapeutic relationship is influenced in part by the relative knowledge of individual practitioners and patients [2, 7]. There are cases in which patients with ME/CFS are forced by lack of available professional expertise to search out information themselves and become "expert patients" [9]. These patients may know more about certain aspects of their health than their practitioners causing a

shift from the usual power balance. This shift can be intensely uncomfortable for practitioners, especially if their self-concept requires that they be in the role of expert [2, 7]. Practitioners whose professional ego does not depend upon being all-knowing may be better able to tolerate this reality. They may, in fact, appreciate the time saved when patients bring them useful, referenced information.

Intervention 4: Clarify gaps in expertise and learn more

Regardless of the relative knowledge of practitioners and patients, practitioners remain responsible for setting the parameters of care (defining what they can offer and how it will occur), evaluating information brought by patients, and agreeing to participate only in interventions that they judge to be in their patients' best interests [57]. Since more than 75 % of the patients with ME/CFS have gone outside orthodox medicine for help [58], practitioners need to know about the other treatment their patients are using and at the same time not give advice which is outside their area of expertise. Collaboration is enhanced when practitioners acknowledge patients' expertise and help them evaluate the validity of the available information [35].

Many practitioners tell their patients that they lack the expertise about ME/CFS [2, 51] and make no effort to educate themselves [59]. Given that the prevalence of ME/CFS is estimated variously at 0.02 – 2.54 % of the population [60, 61], pleading ignorance is not acceptable. Practitioners have a duty to provide educated care. This duty is mandated by some medical councils (e.g. the British Medical Council) [57].

Practitioners who feel ill equipped to assist patients with contested conditions such as ME/CFS should, despite the time and effort required, avail themselves of continuing education just as they would when faced with any other medical condition [51, 62].

There are cases in which patients do not actively engage in treatment. This may be due to severe illness burden, cognitive symptoms, and lack of knowledge/education or dependent personality style. In the case of low motivation or dependent personality, the practitioner's role is to assist with motivation. It is not possible to manage any chronic condition without active patient collaboration. Teaching patients with ME/CFS how to optimize sleep, diet, activity, energy conservation and pain has been shown to improve function [63, 64].

Motivational interviewing strategies can be helpful in this case. An example is discussing the pros and cons of making active changes versus not making any change. If patients are not ready to make changes, the practitioner should accept this and not force the issue, but express readiness to help if and when patient wishes to move ahead. With this approach, patients have permission to come back when they are ready and able to take an active role. In the case of the severely ill or cognitively impaired patient, the practitioner's role is to engage carers to assist the patient in treatment. Once the patient and/or carer are engaged, an initial therapeutic task is to collaboratively make a problem list and agree on a plan to tackle one or at most two problems at a time. This maintains hope and prevents overwhelm.

Challenge 5: Interacting with patients who feel unheard

Another contextual issue of ME/CFS is that many patients have experienced feeling unheard and invalidated by previous practitioners [65-67]. Iatrogenic trauma can linger from past "therapeutic" encounters [8, 68]. Patients may enter a new therapeutic relationship both fearing and assuming that they will be treated in a

dismissive or disrespectful manner. The fear can manifest as patients presenting their case more "loudly", or with a briefcase full of documentation to prove the validity of their condition, a seemingly endless list of severe complaints or even overt anger at the new practitioner [39]. Patients may also present with a defensive posture or seem to be withholding information due to an expectation of being rejected [33].

These behaviors can be misinterpreted as evidence that patients with ME/CFS are inherently more demanding, confrontational or argumentative than other patients. Many years of clinical experience by these authors suggest that this is not the case. Patients with ME/CFS are, in our experience, equally as motivated as patients with other medical and psychiatric conditions and appreciate the emotional and service support of educated, motivated practitioners [7, 54].

Intervention 5: Listen to the whole story

Despite the time constraints faced by busy front line practitioners, it is worthwhile to listen to and record a patient's whole story at least once [41]. This may take several sessions and considerable patience. However, once patients feel heard, they will be much more understanding of the practitioner's needs to set limits and structure during future appointments. In many jurisdictions it is possible to schedule and bill for longer appointments for complex patients and most patients with ME/CFS meet the criteria for complexity. Listening to the whole story, taking notes and asking for relevant clarification lets patients know that the practitioner is concerned enough to get a full picture of their condition [40, 69], even the bits that are odd or surprising. Asking "is there anything else?" until the patient responds "no that is everything" ensures that the practitioner has not missed anything important and that the patient is finished.

Asking new patients to write a short, written, medical history prior to the first appointment is helpful. This saves valuable time especially for patients with long, complicated histories and/or cognitive difficulties. Many patients begin the therapeutic process while writing. They begin seeing patterns in their history that they had not seen before and thereby start gaining perspective.

Challenge 6: Managing the gap between needed and available services

In every health care system there is a gap between the ideal and what is affordable to the individual, insurance company or public health care system. When there is general agreement as to what the best treatments are (e.g. in heart disease and cancer), the gap between patients' needs and available services may be relatively small and non-conflicted.

In the case of contested conditions such as ME/CFS the gap is much larger. Since few front line practitioners have had any education about ME/CFS, they do not have the skills required to make accurate, timely diagnoses and oversee treatment [3]. There is a lack of needed services for ME/CFS at all levels of the health care system [70-72]. Services, which are diagnosis-based, are often unavailable to patients with contested disorders. This may include necessary medical and psychological investigation, access to rehabilitation and home care, safe housing, prepared food, disability payments and community support [54]. Unmet needs can lead to anger and frustration on the part of patients, family members and practitioners. They may believe (often with good reason) that if a certain service were available the patient's suffering would be lessened.

Intervention 6: Collaboratively advocate for services

If a practitioner believes that services requested by his/her patient are not required (e.g. MRI to rule out MS or psychometric testing to measure cognitive dysfunction) then it is extremely helpful to ask the patient or family to explain further why they feel the test or service would be helpful. Often a more complete and transparent explanation on the part of the practitioner alleviates the ongoing tension. An explanation that the feared diagnosis is not supported by the clinical picture or that the test in question will not change the treatment plan can be helpful. The practitioner must listen to and understand the patient's view before offering a reply.

Another contextual issue is that sometimes testing is not medically indicated but is required to qualify a patient for needed services or disability support. In these cases, practitioners should make the necessary referrals just as they would for patients with any other medical condition. When practitioners agree with a patient that more service is required, they should collaborate with the patient to advocate for the service [43, 54, 73, 74]. The patient may have access to useful information in this regard from friends, family or support group leaders who have faced similar challenges and have been successful in acquiring needed services.

Limitations

This paper has methodological and empirical limitations. Experience-based knowledge was collected from our own patients and colleagues over many years. These patients were not randomly selected nor was standardized data collection used. Therefore, the identified challenges may not reflect the experience of all patients or practitioners. On the other hand, experience based knowledge is rich and was developed over years and in different professional contexts in two countries. Our experience-based knowledge is supported by the literature – both related to persons experiencing ME/CFS and within the general psychotherapy literature. The practice model presented needs to be empirically validated to see if it is generally useful.

Conclusion

Both patients with ME/CFS and their practitioners are likely to misinterpret the lack of therapeutic satisfaction as being caused by the other party rather than being due to lack of adequate medical knowledge, diagnosis and treatment options. Through patient-centered interviewing, and open and transparent collaboration about the difficulties in understanding and managing ME/CFS, patients and practitioners can form an alliance. Together they can formulate and carry out a relevant, individual management plan and continually re-evaluate the plan and the patient's progress. This collaboration may occur independent of a practitioner's theoretical orientation as long as there is a genuine openness to working "with" the patient as a whole individual.

Our clinical experience is that working with ME/CFS patients is a very rewarding experience. We believe this work can become more generally appreciated and valued if practitioners develop the following abilities:

- Validate the patient's experience and discuss differences in opinion.

- Admit the uncertainty about etiology, pathophysiology and best management and validate the patient's perspective.
- Admit the limitations of one's knowledge and learn more as needed.
- Acknowledge the value of patients' expertise.
- Listen to the whole story and understand patients' lived experience.
- Limit expectations for rapid improvement and help patients find hope despite illness severity.
- Form a coalition with the patient and patient advocates to access needed services.

We hope that these ideas will stimulate discussion and research about the best interventions to develop and maintain therapeutic relationships between patients with ME/CFS and health care practitioners.

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