MEDICAL PROVIDERS' VIEWS OF MEDICALLY UNEXPLAINED ILLNESS AND

MEDICALLY UNEXPLAINED SYMPTOMS

By

Jennifer Serene Harsh

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Director of Dissertation: Jennifer L. Hodgson, PhD

Department of Child Development and Family Relations

Patients who present with medically unexplained illnesses or medically unexplained symptoms (MUI/S) tend to be higher utilizers of healthcare services and have significantly greater healthcare costs than other patients, which adds stress and strain for both the patient and provider. Although MUI/S are commonly seen in primary care, and the cost to both patients and the medical system is great, there is not sufficient information available regarding how providers can increase their level of confidence and decrease their level of frustration when working with patients who present with MUI/S. Through a systematic review of the literature and a qualitative phenomenological study, the goals of this dissertation were 1) to report on the qualitative and quantitative research literature regarding medical providers' views of MUI/S, and 2) to discover medical providers' experiences of caring for patients with MUI/S and the personal and professional factors that contributed to their clinical approaches. Results from these studies indicate that providers often experience a lack of confidence in their ability to effectively treat patients with MUI/S, as well as frustration surrounding their encounters with this group of patients. Additional resources that could assist providers in their ability to provide effective care and acquire confidence in their abilities to treat patients with MUI/S need to be developed.

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Jennifer Serene Harsh

APPROVED BY:

DIRECTOR OF
DISSERTATION: _____
                                    Jennifer Hodgson, PhD

COMMITTEE MEMBER: _____
                                    Angela Lamson, PhD

COMMITTEE MEMBER: _____
                                    Mark White, PhD

COMMITTEE MEMBER: _____
                                    Tom Irons, MD

INTERIM CHAIR OF THE DEPARTMENT OF CHILD DEVELOPMENT AND FAMILY
RELATIONS:

_____
                                    Sharon Ballard, PhD

DEAN OF THE GRADUATE SCHOOL: _____
                                    Paul J. Gemperline, PhD

DEDICATION

"I would love to live like a river flows, carried by the surprise of its own unfolding."
- John O'Donohue

This dissertation is dedicated to my cute, loving, kind, compassionate, absolutely awesome grandparents who amaze me every day.

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PREFACE

My illness story, like that of many patients with whom I have had the opportunity to work, began quite unexpectedly and basically turned my life upside-down. Very suddenly, I began feeling tired all the time, mentally foggy, unable to process information or make decisions, nauseous, and very sad or anxious much of the time. I began visiting various doctors in an attempt to discover what was 'wrong' with me. I was told that I had chronic fatigue syndrome, that it was 'all in my head,' and I was probably 'just depressed.' I had no idea what was going on with my body and mind, other than that I must be 'going crazy.' During the time that I was attempting to figure out what was going on with my health, I experienced an overwhelming lack of validation from the medical community and was left with no understanding about why I was feeling so sick. Through a strong determination to uncover what was going on, and through multiple appointments with specialists, I discovered that I had developed chemical sensitivities, a medically unexplained illness.

People who are chemically sensitive react to low levels of chemicals in the environment such as cleaning products, perfume, air fresheners, laundry products such as fabric softeners and detergents, pesticides, formaldehyde in new products such as furniture and clothing, vehicle exhaust, and synthetic chemicals in food, just to name a few. Common reactions include mental confusion, emotional lability, difficulty processing information, short and long term memory loss, stuttering, fatigue, muscle aches, hives, and nausea (Gibson, 2006). As you can imagine, these reactions to products that are so prevalent and widely accepted in our world can limit a chemically sensitive person's ability to lead a 'normal' life. The inability to feel well while shopping for groceries or spending time with friends can lead one to feel very isolated from the world around him or her. For me, this feeling of isolation is far more impacting on an emotional

and social level than any physical symptom I have experienced as a direct result of chemical exposure.

My personal illness story and the educational experience I have had during my journey to become a medical family therapist (MedFT) have driven me to want to add to the body of literature on unexplained illnesses via research and identify interventions and training methods that are inclusive of the patient with MUI/S's biological, psychological, and social experiences.

Being a MedFT means that I am a researcher, educator, and family therapist who believes in approaching health from a systems theory (von Bertalanffy, 1950) and a biopsychosocial (BPS) framework (Engel, 1977). I endorse the idea that to provide more effective treatment for medical patients, providers must consider the interactions between patients' biological, psychological, and social experiences when conceptualizing patients' symptoms and when developing treatment plans. This means to me that, "there are no biological problems without psychosocial implications, and no psychosocial problems without biological implications" (McDaniel, Hepworth, & Doherty, 1992, p. 2). MedFTs are trained to maintain collaborative relationships with medical professionals to ensure that psychosocial aspects of patient care are included in treatment planning. Working as a team, patients, MedFTs, and medical providers can take part in holistic treatment from a BPS-systemic perspective. This collaboration between MedFTs, patients, and medical providers (McDaniel et al., 1992) is one of the most basic tenets of providing successful, effective BPS care.

Collaboration is an instrumental aspect of the MedFT's role. In contrast to the role of a behavioral health specialist receiving referrals for traditional psychotherapy from medical providers or a co-located behavioral health professional working as a specialist in a medical setting, MedFTs are trained to fully integrate into the medical system and provide psychotherapy

and behavioral health support at point of care. Their training provides a skill set that enables MedFTs to become *an integrated part* of the medical team and this integrated team is then able to provide not only medical, but also psychosocial health care.

Through my interactions with patients in both medical and non-medical settings, I have become convinced that utilizing these concepts while working with patients makes it possible to create treatment plans that attend to all aspects of the patient's life, including the lives of their family members and loved ones. Paying attention to all of the biomedical and psychosocial aspects of a person's illness can provide more opportunities for identifying the personal strengths and other supportive factors that can lead to greater wellbeing for patients.

Also, while working in medical settings, I have seen first hand how medical providers' beliefs about the etiology of illness and their perceptions of patients can impact the development of treatment plans and interactions with patients. On an almost-daily basis, I have observed the frustrations that physicians expressed when they found patients with medically unexplained illnesses or medically unexplained symptoms (MUI/S) on their daily list of patients. After witnessing patient/provider interactions, I began to understand how patients' and providers' differences in expectations, varying understandings of etiology, and disagreements about treatment plans hindered the development of a plan that would be satisfying to both parties. I also began to wonder how medical providers' beliefs, biases, and experiences of MUI/S impacted patient care. I saw a unique opportunity to explore what physicians believed made these patients so frustrating to treat and what, if anything, had been helpful in easing their frustration or increasing confidence in their abilities to treat patients with MUI/S.

My co-investigators and I decided that the first step in exploring physicians' experiences with MUI/S patients was to conduct a comprehensive review of the extant literature. Through a

systematic review of the literature on providers' thoughts, beliefs, and experiences of MUI/S, we could begin to see more clearly the gaps in the available research. Thus, we created a second study, a phenomenological study, to gain a more in-depth picture of the personal and professional factors and experiences that contributed to medical providers' thoughts, beliefs, and clinical approaches to treating patients with MUI/S.

In brief, the reason for creating each of these studies was simply to contribute to the literature in a way that would allow for a deeper understanding of the experiences providers have when they treat patients with MUI/S. Through this understanding, we hoped to discover existing opportunities that could be implemented, or new opportunities that could be created, to help medical providers feel confident and prepared to care for this unique group of patients. It is my hope that the results from this dissertation will contribute to the creation of future research, trainings, and courses and, ultimately, to collaborative relationships and integrated care that will be more effective and satisfying for patients and providers.

REFERENCES

Engel, G. L. (1977). The need for a new medical model: A challenge for biomedicine. *Science, 196*, 129-136.

Gibson, P. R. (2006). *Multiple chemical sensitivity: A survival guide*. Churchville, VA: Earthrive Books.

McDaniel, S. H., Campbell, T. L., Hepworth, J., & Lorenz, A. (2005). *Family-oriented primary care (2nd ed.)*. New York, NY: Springer.

von Bertalanffy, L. (1950). An outline of general systems theory. *The British Journal for the Philosophy of Science, 1*(2), 134-165.

CHAPTER ONE: INTRODUCTION

Researchers have estimated that patients with medically unexplained symptoms (MUS) account for 25 to 50 percent of patients seen in primary care, which makes these the most common set of complaints seen by primary care providers (Edwards, Stern, Clarke, & Kasney, 2010). Patients who present with MUS or medically unexplained illnesses (MUI) tend to be higher utilizers of healthcare services and have significantly greater healthcare costs than other patients (Burton, McGorm, Richardson, Weller, & Sharpe, 2012; Reid, Whooley, Crayford, & Hotopf, 2001), which can lead to stress for patients and providers. Both MUI and MUS (MUI/S) are often chronic and lack a definitive biological basis and diagnosis, treatment, and prognosis (Dumit, 2005). Examples of MUI include gulf war syndrome (GWS), chronic fatigue syndrome (CFS), fibromyalgia syndrome (FM), and multiple chemical sensitivity (MCS). The main distinction between MUI and MUS is that while MUS are characterized by one or more physical symptoms, unlike MUI, they do not fit with diagnostic criteria for a recognized unexplained illness and cannot be explained by corresponding physical pathology (Swanson, Hamilton, & Feldman, 2010). The purpose of this chapter is to highlight the need for additional research on provider experiences of MUI/S and to outline the remainder of the dissertation.

Provider Challenges

Medical providers have reported a number of challenges working with patients experiencing MUI/S. For example, MUI/S have been found to lead to provider frustration (e.g., Hartman, Hassink-Franke, Lucassen, van Spaendonck, & van Weel, 2009; Hayes et al., 2010; Lundh, Segesten, & Bjorkelund, 2004; Swoboda, 2008), low confidence in diagnosis and treatment (e.g., Bowen, Pheby, Charlett, & McNulty, 2005; Dixon-Woods & Critchley, 2000; Fitzgibbon, Murphy, O'Shea, & Kelleher, 1997), and a lack of protocols for effective treatment

strategies (e.g., Bieber et al., 2006; Reid et al., 2001; Swoboda, 2008). The lack of and apparent need for more information about MUI/S results in complex and often difficult interactions between medical providers and patients and among the various medical providers who are treating the patients (Hoedeman, Krol, Blankenstein, Koopmans, & Groothoff, 2010). Because of the frequency of MUI/S patient visits to primary care settings (Edwards et al., 2010), and the aforementioned frustrations (e.g., Hayes et al., 2010) and lack of confidence (e.g., Dixon-Woods & Critchley, 2000) that providers often experience when treating patients with MUI/S, research on this topic and, specifically, provider experiences with MUI/S is important. Thus, two research studies were carried out for this dissertation with the goal of contributing to a better understanding of how medical providers experience treating patients who present with MUI/S. The first study was a systematic review of the literature and the second was a qualitative phenomenological research study.

The goals of both projects were in line with the framework developed by The Institute for Healthcare Improvement (IHI). IHI's framework targets what they call the "Triple Aims": improving the patient experience of care (including quality and satisfaction), improving the health of populations, and reducing the per capita cost of healthcare (IHI, 2013). Research carried out for this dissertation was also consistent with the goals of the Patient-Centered Medical Home model, which aims to create care environments that provide quality, coordinated, patient-centered, comprehensive care (Robert Graham Center, 2007).

Theoretical Underpinning

Attribution theory was incorporated into the designs for each study as a lens through which to view the research processes and outcomes. Attributions are the result of cognitive processes that help people apply cause and effect to interactions with their environment

(Martinko, Harvey, & Douglas, 2007). Because of people's innate drive to search for causes of their experiences (Borkowski & Allen, 2003; Weiner, 2008), control their environments (Borkowski & Allen, 2003), and explain or understand the behaviors of self and others (Cranford & King, 2011; Marinko et al., 2007) attributions are assigned to events and occurrences.

The basic tenets of attribution theory can be applied to the healthcare system and more specifically to the behavior of providers who treat patients who have MUI/S. In a healthcare setting, medical providers treat patients based on their attribution (e.g., biomedical, psychological, social) of patients' symptoms. Whether done consciously or unconsciously, providers will attempt to explain why people behave in a certain manner and will attempt to attribute patients' symptoms to a certain cause (e.g., organic illness, psychological difficulty, trauma-related issue). Thus, the treatment recommended for patients may stem from what the provider believes is responsible for causing the symptoms or illness.

With the tenets of attribution theory in mind, the aims of the first study, a systematic review of the extant literature, were to: 1) identify, analyze, and report on the qualitative and quantitative research literature regarding medical providers' views of MUI/S, and 2) recommend future research that could advance the science behind how medical providers attribute MUI/S and interact with patients toward the development of more mutually satisfying treatment plans.

The review resulted in six common themes related to providers' views on MUI/S: (a) differences among providers in their acceptance of or skepticism about MUI/S, (b) varying attributions of MUI/S etiology, (c) diagnostic and treatment differences, (d) providers' reports of difficulties in treating MUI/S patients, (e) difficulties in the provider-patient relationship, and (f) lack of confidence in diagnosing and treating MUI/S. Although the studies reviewed have contributed to the growing body of knowledge on provider views of MUI/S, we found that

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provider demographics, etiological attribution, and frustration related to provider level of confidence with diagnostic and treatment practices was still unclear.

Based on the results of the literature review, we created a phenomenological research study in order to gain a better understanding of medical residents' views of MUI/S. We aimed to explore the following research question: "What are the personal and professional factors and experiences that contribute to medical residents' thoughts, beliefs, and clinical approaches to treating patients with MUI/S?" Through in-depth interviews with medical residents, we gained a better understanding of how they experienced their contact with patients who presented with MUI/S. Specifically, through this study, we identified six common themes discussed by residents during semi-structured interviews: (a) medical education, (b) provider and patient frustrations, (c) integrated care, (d) rewards and benefits, (e) provider/patient relationships, and (f) co-researcher attributions of MUI/S.

The chapters following this introduction provide an in-depth report of how medical residents, the co-researchers in this phenomenological study, perceived MUI/S and experienced their work with patients presenting with MUI/S. The second chapter outlines the process and results of the systematic review of the extant literature on medical provider perceptions of MUI/S, presents a synthesis of review findings, and identifies gaps in the available research. The third chapter details the methodology employed to guide our phenomenological research study, which was created in response to the gaps found during the systematic literature review. The fourth chapter is our second research article, which includes the results of our qualitative study. Finally, chapter five discusses the implications of both studies for medical and behavioral healthcare provider training in MUI/S, future research, and healthcare policy development.

REFERENCES

Bieber, C., Muller, K. G., Blumenstiel, K., Schneider, A., Richter, A., Wilke, S., … Eich, W.

    (2006). Long-term effects of a shared decision-making intervention on physician-patient

    interaction and outcome in fibromyalgia. A qualitative and quantitative 1 year follow-up

    of a randomized controlled trial. *Patient Education and Counseling*, *63*,

    357-366. doi:10.1016/j.pec.2006.05.003

Borkowski, N. M., & Allen, W. R. (2003). Does attribution theory explain physicians'

    non acceptance of clinical practice guidelines? *Hospital Topics, 81*(2), 9-21.

Bowen, J., Pheby, D., Charlett, A., & McNulty, C. (2005). Chronic fatigue syndrome: A survey

    of GPs' attitudes and knowledge. *Family Practice Advance Access*, 22, 389-393.

    doi:10.1186/147-2296-6-49

Burton, C., McGorm, K., Richardson, G., Weller, D., & Sharpe, M. (2012). Healthcare costs

    incurred by patients repeatedly referred to secondary medical care with medically

    unexplained symptoms: A cost of illness study. *Journal of Psychosomatic Research, 72*,

    242-247. doi:10.1038/jid.2012.12

Cranford, C., & King, C. R. (2011). Nurse practitioner students' perceptions of fibromyalgia

    pain and quality of life. *Medsurg Nursing, 20*(4), 169-177.

Dixon-Woods, M., & Critchley, S. (2000). Medical and lay views of irritable bowel syndrome.

    Family Practice, 17(2), 108-113. doi:10.1093/fampra/17.2.108

Dumit, J. (2005). Illnesses you have to fight to get: Facts as forces in uncertain, emergent

    illnesses. *Social Science & Medicine, 62*, 577-590. doi:10.1016/j.socscimed.2005.06.018

Edwards, T. M., Stern, A., Clarke, D. D., Ivbijaro, G., & Kasney, L. M. (2010). The treatment of

    patients with medically unexplained symptoms in primary care: A review of the

literature. *Mental Health in Family Medicine, 7*, 209-221.

Fitzgibbon, E. J., Murphy, D., O'Shea, K., & Kelleher, C. (1997). Chronic debilitating fatigue in Irish general practice: A survey of general practitioners' experience. *British Journal of General Practice, 47*, 618-622.

Hartman, T. C., Hassink-Franke, L. J., Lucassen, P. L., van Spaendonck, K. P., & van Weel, C. (2009). Explanation and relations. How do general practitioners deal with patients with persistent medically unexplained symptoms: A focus group study. *BMC Family Practice, 10*(68). Retrieved from http://www.biomedcentral.com/1471-2296/10/68/. doi:10.1186/1471-2296-10-68

Hayes, S. M., Myhal, G., Thorton, J. F., Camerlain, M., Jamison, C., Cytryn, K. N., & Murray, S. (2010). Fibromyalgia and the therapeutic relationship: Where uncertainty meets attitude. *Pain Resource Management, 15*(6), 385-291.

Hoedeman, R., Krol, B., Blankenstein, A. H., Koopmans, P. C., & Groothoff, J. W. (2010). Sick-listed employees with severe medically unexplained physical symptoms: Burden or routine for the occupational health physician? A cross sectional study. *BMC Health Services Research, 10*, 305-312. doi:10.1186/1472-6963-10-305

Institute for Healthcare Improvement (2013).The IHI triple aim. Retrieved from http://www.ihi.org/offerings/Initiatives/TripleAim/Pages/default.aspx

Lundh, C., Segesten, K., & Bjorkelund, C. (2004). To be a helpless helpoholic – GPs' experiences of women patients with non-specific muscular pain. *Scandinavian Journal of Primary Health Care, 22,* 244-247. doi:10.1080/02813430410006756

Martinko, M. J., Harvey, P., & Douglas, S. C. (2007). The role, function, and contribution of attribution theory to leadership: A review. *The Leadership Quarterly, 18*, 561-585.

doi:10.1016/j.leaqua.2007.09.004

Reid, S., Whooley, D., Crayford, T., & Hotopf, M. (2001). Medically unexplained
symptoms- GPs' attitude toward their cause and management. *Family Practice,*
18(5), 519-523. doi:10.1093/fampra/18.5.519

Robert Graham Center (2007). *The patient centered medical home*. Retrieved from
http://www.graham-center.org/PreBuilt/PCMH.pdf

Swanson, L. M., Hamilton, J. C., & Feldman, M. D. (2010). Physician-based estimates of
medically unexplained symptoms: A comparison of four case definitions. *Family*
Practice, 27, 487-493.

Swoboda, D. A. (2008). Negotiating the diagnostic uncertainty of contested illnesses:
Physician practices and paradigms. *Health: An Interdisciplinary Journal for the*
Social Study of Health, Illness, and Medicine, *12*(4), 453-478.
doi:10.1177/1363459308094420

Weiner, B. (2008). Reflections on the history of attribution theory and research: People,
personalities, publications, problems. *Social Psychology, 39*(3), 151-156.

CHAPTER TWO: MEDICAL PROVIDERS' VIEWS OF MEDICALLY UNEXPLAINED

ILLNESS AND MEDICALLY UNEXPLAINED SYMPTOMS: A SYSTEMATIC REVIEW

Medically unexplained illnesses (MUI) are fraught with medical, social, and political

uncertainty (Dumit, 2005). Most often they are chronic and lack a definitive biological basis and

diagnosis, treatment, and prognosis (Dumit, 2005); examples include gulf war syndrome (GWS),

chronic fatigue syndrome (CFS), fibromyalgia (FM), and multiple chemical sensitivity (MCS;

Swoboda, 2008). While MUI have been reported to be among the most prevalent difficulties seen

in primary care patients (Johnson, 2010), research on MUI is sparse, largely due to lack of

funding (Swoboda, 2008). The ambiguous etiology of these illnesses and the lack of information

consequently make MUI difficult for many medical providers to diagnose and treat (Swoboda,

2008). Without a definite diagnosis and an agreed-upon treatment protocol, acceptance of MUI

by the medical system is often difficult (Dumit, 2005).

As with MUI, patients with medically unexplained symptoms (MUS) tend to experience

the medical community similarly (e.g., Horton-Salway, 2007; Reid, Wessely, Crayford, &

Hotopf, 2001). For the purpose of this paper, the main distinction between MUI and MUS is that

MUI are characterized by a cluster of unexplained medical symptoms that fit with the diagnostic

criteria for a recognized unexplained illness (e.g., CFS, MCS), while MUS are characterized by

one or more physical symptoms that cannot be medically explained and do not fit with diagnostic

criteria for a recognized unexplained illness (e.g., fatigue, diffuse pain). However, people with

either tend to be higher utilizers of healthcare services and have significantly greater healthcare

costs than other patients (Burton, McGorm, Richardson, Weller, & Sharpe, 2012; Reid et al.,

2002), which add stress and strain for both patient and provider. Researchers have estimated that

25-50 percent of patients seen in primary care present with MUS, which makes MUS the most

common set of complaints seen by primary care providers (Edwards et al., 2010). Thus, if no more attention is given to the issue of how to effectively treat this group of patients, a large number of providers and patients may continue to experience unproductive and frustrating interactions.

Patient and Provider Difficulties

Challenging interactions with the medical system have the potential to increase stress and trauma for people living with MUI and MUS (MUI/S) (Gibson, 2006), and treating patients' MUI/S can be extremely difficult and frustrating for providers (Hartman, Hassink-Franke, Lucassen, van Spaendonck, & van Weel, 2009; Swoboda, 2008). Thus, it is important to understand how each of these groups experiences its interactions with the other. For example, people living with MUI/S may experience a number of difficulties while coping with these illnesses (e.g., lost wages for time away from work, difficulty in social and relational aspects of their lives) and when attempting to receive medical treatment (Gibson, 2006; Horton-Salway, 2007). Stress can result from changes in lifestyle that are often necessary to accommodate the more commonly associated symptoms (e.g., fatigue, pain, mental confusion) (Gibson, 2006; Kilshaw, 2008). Subsequently, people with MUI/S may experience a lack of validation by the medical community, be given referrals for mental health treatment while attempting to seek out medical care, receive inappropriate treatments or misdiagnoses (Edelson & Statman, 1998), and be denied social security claims and reimbursement from insurance companies for medical care (Dumit, 2006).

Medical providers have reported a number of challenges working with patients experiencing MUI/S. For example, MUI/S have been found to lead to provider frustration (e.g., Hayes et al., 2010; Lundh, Segesten, & Bjorkelund, 2004) and low confidence in treatment and

diagnosis (e.g., Bowen, Pheby, Charlett, & McNulty, 2005; Dixon-Woods & Critchley, 2000; Fitzgibbon, Murphy, O'Shea, & Kelleher, 1997). Additionally, when working with patients with MUI/S, providers may find that protocols for effective treatment strategies are lacking (e.g., Bieber et al., 2006; Reid, Whooley, Crayford, & Hotopf, 2001; Swoboda, 2008), resulting in frustrating and difficult interactions between medical providers and patients with MUI/S, and among different medical providers treating patients with MUI/S (Hoedeman, Krol, Blankenstein, Koopmans, & Groothoff, 2010).

Overall, researchers have focused their attention on both patients' experiences with and seeking treatment for MUI/S (e.g., Madden & Sim, 2006; Nettleton, 2006; Werner & Malterud, 2003) and on providers' acceptance or rejection of MUI/S, frustration, and feelings of uncertainty regarding their experience with MUI/S (e.g., Asbring & Narvanen, 2003; Gibson & Lindberg, 2011; Lundh et al., 2004). Even though researchers have looked at provider differences in etiological attribution of MUI/S (e.g., biological, psychosocial) and feelings of uncertainty with regard to diagnosing and treating patients with MUI/S, they have failed to study the source and impact of provider attribution and biases on their ensuing diagnostic and treatment strategies. An expanded understanding of providers' attribution of what causes MUI/S and how that attribution leads to choice of diagnoses and subsequent treatment may increase the likelihood of creating new tools, such as education programs and resources, to assist providers in negotiating the uncertainty of working with MUI/S. In turn, these tools may increase providers' ability to help patients negotiate the uncertainty of living with MUI/S and may have the potential to increase patient-provider satisfaction with the treatment experience.

Therefore, the purpose of this review is to identify, analyze, and report on literature regarding medical providers' thoughts, beliefs, and experiences caring for patients with MUI/S.

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Attribution theory will be used as a framework for interpreting the literature and helping to advance research in this area.

Attribution Theory

Attribution theory, often used in social psychology research (Weary, Rich, Harvey, & Ickes, 1980), was first proposed by Fritz Heider (1958). The use of attribution theory has expanded since Heider's seminal work was published, and a number of individuals have contributed to the growing body of literature (e.g., Jones et al., 1972; Kelley, 1960; Weiner, 2008). It has been applied to attitudes toward a number of illnesses including addiction (Switzer & Boysen, 2009), cancer (Mosher & Danoff-Burg, 2008), and HIV/AIDS (Cobb & DeChabert, 2002).

Attributions are the result of cognitive processes that help people apply cause and effect to interactions with their environment (Martinko, Harvey, & Douglas, 2007). They are assigned to any event or occurrence due to people's innate drive to search for causes (Borkowski & Allen, 2003; Weiner, 2008), control their environments (Borkowski & Allen, 2003), and explain or understand the behaviors of self and others (Cranford & King, 2011; Marinko et al., 2007).

There are two main categories of attributions that people ascribe to events or behaviors: external and internal. External attributions assign the causality of an event or situation to an outside force. The outside force is thought to be somehow responsible for the event or behavior (Heider, 1958). Conversely, with internal attributions the cause is assigned to factors present within a person, and the person is viewed as solely responsible for the behavior or event (Weiner, 1979). The difference between external and internal attributions can be thought of as the level of control the person has over the event or behavior. External attribution denotes less control while internal attribution ascribes control to intrapersonal mechanisms.

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There are three main steps that make up the attribution process (Heider, 1958). In the first step, a person perceives an action as a behavior or a circumstance. Second, the person judges another's action according to his or her own individual biases. Third, the person draws a conclusion about the influences (external or internal) of the behavior based on his or her individual biases (Cranford & King, 2011). Conclusions are based on biases and beliefs whether or not the person's beliefs are valid or applicable to the situation (Borowski & Allen, 2003).

Attribution Theory and Medically Unexplained Illnesses/Symptoms

The application of attribution theory to provider experiences of patients with MUI/S can be seen in the example that follows, which applies the same three step attribution process described above.

Step 1: Provider judges the action as a behavior or circumstance. A physician begins discussing the acute pain experienced by a patient with fibromyalgia syndrome. Since the physician does not believe in the diagnosis of fibromyalgia syndrome, the physician runs a number of tests and hypothesizes different diagnoses for the presenting symptoms. After each test comes back negative, the provider attributes the symptoms to a medically unexplained cause due to the beliefs and information the provider has about the medical illness.

Step 2: Provider judges the intention of the patient's behavior based on biases. Having attributed the cause of the symptoms to medically unexplained factors, the physician may then, based on his or her perceptions of the patient and his or her own biases, determine that since there is no medical proof for the condition, the patient must be making up the symptoms in an attempt to receive pain medication or that the patient is somatizing psychological stress in the form of physical symptoms.

Step 3: Provider makes a conclusion about influence of behavior based on biases. Since the provider has attributed the cause of the illness to the patient making up symptoms, the provider may not prescribe medication for the patient and may refer the patient to mental health services in lieu of performing any more biomedical tests or examinations

The basic tenets of attribution theory can be applied to the healthcare system and more specifically to the behavior of providers who treat patients who have MUI/S. Based on attribution theory, healthcare providers, like anyone else, will assign attributions to the behaviors and experiences of their patients due to the provider's own innate drive to search for causes (Weiner, 2008) and to control their own environment (Borkowski, 2003). Whether done consciously or unconsciously, providers will attempt to explain why people behave in a certain manner and will attempt to attribute patients' symptoms to a certain cause (e.g., organic illness, psychological difficulty, trauma-related issue). Patients' treatments may likely stem from what the provider believes is responsible for causing the symptoms or illness.

Aims

The aims of this systematic review are to: 1) identify, analyze, and report on the qualitative and quantitative research literature regarding medical providers' views of MUI/S, and 2) recommend future studies needed to advance the science behind how medical providers attribute unexplained MUI/S and interact with patients toward the development of a mutually satisfying treatment plan.

Method

The methodology for this systematic review was based on Cooper's seven-step model for the research synthesis process (2010). Four electronic databases were searched: PsychInfo, Medline via Pubmed, Biomedical Reference Collection, and Ovid/PsychArticles. Articles

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published before May 2012 that met the search criteria were included in this review. The search strategy and keywords were developed for use in PsychInfo and were replicated for each subsequent database. Each search term was related to providers' perceptions of medically unexplained illnesses or symptoms. A full list of search terms can be found in Table 1. Reference lists of relevant articles were reviewed for additional studies, which were then retrieved by searching the databases listed above.

Article Selection

Articles were selected if they: a) were published in English, b) focused on medically unexplained illness or symptoms, c) included information about medical providers' views of medically unexplained illness or symptoms, and d) were reports on original research studies. Qualitative and quantitative studies were included in the initial search. Articles were excluded if they: a) were discussions of theory or treatment models and did not include an original research study or b) were reviews, editorials, or book reviews.

Results

To add rigor to the identification of relevant literature, two reviewers performed the database article search and screened all titles and abstracts independently. In the initial search step, reviewers performed a search of four databases using the search criteria above (Figure 1). The first step resulted in 4,271 articles. Each reviewer then selected articles from the 4,271 initial articles that were included in the full text review based on titles and abstracts. After screening the titles and abstracts, 32 articles were determined to have met the inclusion criteria. Of the 32 articles, the first reviewer found four articles that were not found by the second reviewer, while the second reviewer found three additional articles that were not found by the first reviewer. Reference lists of each article that met search criteria were then reviewed by both reviewers for

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possible additional articles that met the inclusion criteria for this study. An additional 13 articles were identified from the reference lists and were added to the review. Further, a review of the references from these 13 articles was completed. Two studies were identified as meeting the inclusion criteria and were added to the review. A reference list review of these two articles did not result in identification of additional studies that met the search criteria. Discrepancies between reviewers regarding the articles included for the full text review were resolved through discussion. After a full-text review of all 47 articles, 36 met the inclusion criteria and were selected for the review.

Studies differed in aspects such as participant characteristics, geographic location, and research design. The studies were designed to focus on a variety of specific illnesses or sets of symptoms. However, each of the studies included in this review involved medical providers' perceptions of MUI/S in some form. Table 2 is used to further describe each study's characteristics and main findings. Some researchers included both patients' and providers' experiences in their studies. However, since the focus of the current review was medical providers' perceptions only, patients' perceptions of their illness experience (see Dumit, 2006; Edelson & Statman, 1998; Gibson, 2006; Horton-Salway, 2007; Kilshaw, 2008) were not included.

In the following section, the results from each study are grouped into six main themes, each of which were represented in a majority of the studies reviewed, and are then critiqued in order to highlight opportunities for advancements in research. Themes include differences between providers in their acceptance or skepticism of MUI/S, varying attributions of MUI/S etiology, diagnostic and treatment differences, providers' reports of difficulties in treating MUI/S patients, difficulties in the provider-patient relationship, and a lack of confidence with

diagnosing and treating MUI/S. Attribution theory (Heider, 1958) will be used as a lens through which to look at the current research on MUI/S as well as to identify gaps and potential future research opportunities to broaden our current understanding of providers' experiences with MUI/S.

Summary of Results by Theme

  Acceptance and skepticism. In the 36 studies reviewed, providers expressed both skeptical and accepting views regarding the validity of MUI/S (e.g., Asbring & Narvenen, 2003; Fitzgibbon et al., 1997; Ho-Yen, 1991). In 16 percent of the studies reviewed, researchers found providers held skeptical views of MUI/S (e.g., Asbring & Narvanen, 2003; Bowen et al., 2005; Cranford & King, 2011), while in eight percent of the studies reviewed providers reported acceptance of MUI/S as a distinct clinical entity (Denz-Penhey & Murdoch, 1993; Ho-Yen, 1991; Thomas & Smith, 2005).

  Although researchers focused on the acceptance or rejection of MUI/S as a distinct clinical entity, the reason for providers' acceptance or rejection was not discussed. Simply knowing how many providers accept or reject MUI/S as recognizable conditions may be valuable information to aid in discovering how to tailor appropriate education programs or resources for providers who work with this population of patients. However, researchers did not go further to discover why providers are accepting or skeptical of MUI/S. Discovering what underlies providers' acceptance or rejection of MUI/S may enhance the tools and resources to assist providers in caring for this patient population in a more appropriate and effective manner.

  Attribution of etiology. Researchers reported that providers described psychosocial reasons for the onset of MUI/S in approximately 35 percent of the 36 studies included in this review (e.g., Asbring & Narvanen, 2003; Dixon-Woods & Critchley, 2000; Prins, Bleijenberg,

Rouweler, van Weel, & van der Meer, 2000; refer to Table 3). Providers who attributed MUI/S to internal, psychosocial causes believed that patients' psychiatric symptoms caused the MUI/S (Jason, Taylor, & Stepnek, 2001; Reid et al., 2001). Providers mentioned stress (Gomez, Schvaneveldt, & Staudenmayer, 1996), patients overworking (Cho, Menezes, Bhugra, & Wessely, 2008), psychological factors such as anxiety and depression (Dixon-Woods & Critchley, 2000), social problems (Wileman, May, & Chew-Graham, 2002), and being emotionally upset (Gomez et al., 1996) as possible causes of MUI/S.

Providers who sought these internal, psychosocial explanations for MUI/S reported that they believed patients were looking for a medical label for their every day problems and also thought that patients were persuaded by what they heard and read in the media (Horton-Salway, 2007). Additionally, providers believed that MUI/S were the result of the medicalization of distress and patients' decreased tolerance of largely benign symptoms (Wileman et al., 2002). A difference in the name of the unexplained illness (e.g., Chronic Fatigue Syndrome vs. Myalgic Encephalomyelitis) was positively correlated with psychosocial attribution for the MUI/S (Jason et al., 2001). If the unexplained illness was called Chronic Fatigue Syndrome, study participants were more likely to deem it psychosocial in origin, while participants viewed the name Myalgic Encephalomyelitis as biomedical in origin (Jason et al., 2001). Subsequently, providers had higher mental health service referral rates for the patients whose symptoms were believed to be primarily stemming from psychosocial etiology (Sharpe et al., 1994; Steven et al., 2000).

In eight percent of the studies reviewed, instead of psychosocial explanations regarding etiology, providers attributed MUI/S to external, biomedical causes (e.g., Hellstron, Bullington, Karlsson, Lindqvist, & Mattsson, 1998; Jason et al., 2001; Kroese, Schulpen, Sonneveld, & Vrijheof, 2008; refer to Table 3). Providers relied on their biomedical knowledge and biomedical

treatments to help patients (Helstrom et al., 1998; Krose et al., 2008) and they perceived patients as wanting external, biomedical explanations for their MUI/S rather than internal, psychosocial ones (Lundh et al., 2004). Providers indicated that observable physical pathology, such as results from biomedical lab tests, was at the top of the "moral hierarchy" when it came to causation for MUI/S (Wainwright, Calnan, O'Niel, Winterbottom, & Watkins, 2006, p. 79).

In addition to psychosocial and biomedical attributions about the causes of MUI/S, in 14 percent of the 36 articles included in this study researchers reported that medical providers believed etiology was a combination of external, biomedical factors and internal, psychosocial factors (e.g., Gibson & Lindberg, 2011; Philips, 2010; Richardson et al., 2001; refer to Table 3). However, even though these providers believed symptoms were both biomedical and psychosocial in origin (Skovbjerg, Johansen, Rasmussen, Thorsen, & Elberling, 2009), some believed that neither the biomedical nor the psychosocial paradigm contributed to their understanding of the patients' problems (Lundh et al., 2004).

While researchers reported on providers' differing attributions regarding the etiology of MUI/S, they did not discuss in any depth the factors that providers attributed to their diagnostic or treatment decisions. Also, the manner in which attribution differences between providers contributed to a greater or lesser understanding of patients' problems and treatment decisions was not studied.

Diagnosis and treatment differences. In addition to differences in attributions regarding etiology, providers differed in their decision-making processes about diagnoses and treatments as well as what the diagnoses were and what the treatments should be. Decision-making differences, or *how* the provider comes to an understanding of what is causing the patient's presenting complaints, or how to treat the complaints, were reported in eight percent of the 36

studies reviewed. Diagnostic differences between providers were found in five percent of the studies, and treatment differences were found in 16 percent of the studies reviewed (e.g., Cho et al., 2008; Fitzgibbon et al., 1997; Krose et al., 2008; refer to Table 3).

Based on the studies reviewed, providers draw on their experience and knowledge to create a working definition about MUI/S (Dixon-Woods & Critchley, 2000). They used inductive reasoning strategies to ascertain a diagnosis and approach uncertainty in dealing with MUI/S in different ways (Philips, 2010). Providers who diagnose MUI/S tend to use different decision-making strategies than those who choose not to diagnose MUI/S. For example, researchers found that those who diagnosed MUI/S thought beyond the current medical disease models (Swoboda, 2008).

Researchers found that providers differed considerably in their treatment strategies for MUI/S (Fitzgibbon et al., 1997; Krose et al., 2008) in 16 percent of the 36 articles reviewed. Some providers used biomedical treatments while others used psychosocial treatments (Krose et al., 2008). Examples included antidepressants (Thomas & Smith, 2005), exercise therapy, physical therapy, analgesics (Krose et al., 2008), and mental health counseling (Cho et al., 2008). Providers also utilized referrals to other disciplines (e.g., psychology, physical therapy) to assist in the treatment of MUI/S patients (Krose et al., 2008). Providers reported deferring to providers from other disciplines for helpful or new information to assist in the provision of treatment (Richardson et al., 2001).

Though researchers discussed differing decision making strategies used by providers who treat patients with MUI/S (e.g., Swoboda, 2008), they did not mention how these decision making strategies influenced providers' reported experiences of working with patients with MUI/S. Researchers did not mention how, if at all, patients and providers made decisions about

treatment together. Also, reference to how the provider/patient relationship was influenced by diagnosis and treatment strategies was not included in the studies reviewed.

Difficult patients. In approximately 24 percent of the studies reviewed, providers reported experiencing MUI/S or patients who presented with MUI/S as difficult to work with (e.g., Horton-Salway, 2007; Prins et al., 2000; Raine, Carter, Sensky, & Black, 2004; refer to Table 3). They believed that these patients took more time and had more problems with communication and cooperation (Prins et al., 2000). Patients with MUI/S were perceived to have undesirable traits and created greater conflict when discussing cause and treatment options (Raine et al., 2004). Providers felt that working with MUI/S patients was burdensome (Raine et al., 2004); some providers perceived patients with MUI/S to be more controlling (Salmon, Ring, Dorwrick, & Humphris, 2005), and it was difficult for providers to distinguish between patients who were genuine sufferers with external causation and those with internal causation who jumped on the "bandwagon" (Horton-Salway, 2007, p. 909).

Viewing patients as difficult was associated with an absence of a diagnosis that could explain symptoms, failure of treatments to relieve symptoms, and providers feeling their ability to care for patients was inadequate (Sharpe et al., 1994). A high level of patient need for emotional support (Salmon et al., 2005) and patient self-diagnosis (Scott, Deary, & Pelosi, 1995) also led providers to believe patients with MUI/S were more difficult.

In 19 percent of the studies reviewed, providers reported a great deal of frustration regarding their work with patients who presented with MUI/S (e.g., Dixon-Woods & Crichley, 2000; Hayes et al., 2010; Hoedman, Krol, Blankenstein, Koopmans, & Groothoff, 2010; refer to Table 3). Researchers reported that some providers were frustrated by the absence of effective treatment and medical understanding (Dixon-Woods & Critchley, 2000) and their lack of

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adequate tools to help patients with MUI/S (Lundh et al., 2004), while others reported that their

frustration stemmed from the greater time commitment that often accompanies working with

MUI/S patients (Hayes et al., 2010). Providers reported needing additional support to begin to

manage the frustration that surrounds treating this group of patients (Wileman et al., 2002).

In the studies included in this systematic review, providers also reported more specific

challenges along with the general themes of finding MUI/S patients difficult (e.g., Prins et al.,

2000) and frustrating to work with (e.g., Hayes et al., 2010). Providers reported that their ideal

physician role was challenged by patients with MUI/S (Asbring & Narvanen, 2003) and they

disliked working with these patients because they did not like situations in which they did not

feel in control (Hellstrom et al., 1998). Providers reported that they believed the balance of

power was often with the patient when working with this population and the patients were,

therefore, difficult to manage (Wileman et al., 2002). Additionally, they reported feeling

inadequate or helpless when they cared for difficult-to-treat patients (Sharpe et al., 1994) and felt

powerless when they believed symptoms were social, or external in origin (Wileman et al.,

2002).

Although the providers studied noted that these patients tended to be difficult to treat,

there is a lack of research on what influenced these providers' attributions. Attribution theory

may provide the basis for a model by which to better understand why many providers experience

MUI/S and patients who present with MUI/S as difficult (e.g., Prins et al., 2000) or frustrating to

work with (e.g., Hayes et al., 2010). Researchers have found a number of reasons providers

experience interactions with MUI/S patients as largely negative. However, a model that attempts

to explain how provider attribution of MUI/S and how patient/provider characteristics (e.g.,

gender, age, location) influence levels of frustration and the quality of interactions with patients does not yet exist.

Provider-patient relationship. The provider-patient relationship was another frequent theme and was discussed in 22 percent of the articles included in this review (e.g., Hartman et al., 2009; Horton et al., 2010; Prins et al., 2000). Researchers found that the provider-patient relationship in MUI/S cases was reportedly difficult to establish and maintain (Hartman et al., 2009). The provider-patient relationship was found to be adversely impacted by doubt about the diagnosis, physician frustration (Chew-Graham, Cahill, Dowrick, Wearden, & Peters, 2008), and a lack of sympathy for MUI/S patients (Prins et al., 2000). Providers noted difficulty switching between the biomedical and psychosocial paradigms with this group of patients (Wainwright et al., 2006) and stressed the importance of good communication (Hellstron et al., 1998) and listening in order to build trusting relationships (Horton et al., 2010).

While provider characteristics that lead to a greater likelihood of providers' experiencing more positive attitudes toward working with MUI/S patients were mentioned in the articles reviewed (e.g., being male, knowing someone socially with MUI/S, more than five years in the same practice location; Bowen et al., 2005; Hartz et al., 2000), the relationship between characteristics such as socioeconomic status of patients, provider practice location, age of provider, years in practice and the provider/patient relationship was not discussed. Also, the techniques used by providers to build strong communication and a positive relationship with MUI/S patients were not mentioned. Discovering techniques that have assisted providers in creating and maintaining healthy relationships with MUI/S patients may assist in the creation of useful education programs and resources.

Lack of confidence with diagnosis and treatment. Providers reported feeling ill equipped to work with patients with MUI/S (Wileman et al., 2002). In one study, a majority of the participants reported sufficient knowledge to make a MUI/S diagnosis (Denz-Penhey & Murdoch, 1993); however, participants in other studies reported feeling unprepared to manage and diagnose MUI/S from their medical training alone (Chew-Graham et al., 2008; Gibson & Lindberg, 2011). In 24 percent of the studies reviewed, providers reported a desire to improve their knowledge of MUI/S (e.g. Bieber et al., 2006; Chew-Graham et al., 2008; Cranford & King, 2011; Hartz et al., 2000; refer to Table 3). Providers welcomed advice from other healthcare professionals (Thomas & Smith, 2005) and requested more knowledge and resources about diagnostic tools and MUI/S (Skovbjerg et al., 2009). In addition to medical resources, providers reported attempting to access additional knowledge through multiple sources (Gibson & Lindberg, 2011), such as information about MUI/S in the media, observations of patients outside of the exam room, and through their own personal experience (Chew-Graham et al., 2008).

Due in part to the aforementioned factors, such as uncertainty regarding etiology (e.g., Chew-Graham et al., 2008; refer to Table 3) and lack of knowledge regarding diagnostic tools (Skovbjerg et al., 2009), providers reported a lack of confidence in diagnosing MUI/S and treating MUI/S in 19 and 30 percent of the reviewed studies, respectively (e.g., Bowen et al., 2005; Raine et al., 2004; Steven et al., 2000; refer to Table 3). The lack of clear diagnostic criteria (Steven et al., 2000), effective treatment protocols, and poor medical understanding of MUI/S and management strategies (Dixon-Woods & Critchley, 2000; Gibson & Lindberg, 2011; Lundh et al., 2004; Reid et al., 2001; Prins et al., 2000) were contributing factors to providers' lack of confidence with treatment and diagnosis of MUI/S. Providers' dissatisfaction with the quality of care they provided to patients (Fitzgibbon et al., 1997), mismatched perceptions and

unmet needs on the parts of the patients and providers (Hayes et al., 2010), and uncertainty surrounding MUI/S (Horton et al., 2010) were additional factors that led to their decreased confidence.

In 19 percent of the studies reviewed, research teams addressed providers' perceived lack of confidence in their ability to diagnose and treat patients with MUI/S (e.g., Fitzgibbon et al., 1997; Hartz et al., 2000; Horton et al., 2010). However, only one group of researchers discussed a provider training program that was helpful in decreasing providers' negative feelings regarding patients with MUI/S (Bieber et al., 2006). The remaining studies reviewed failed to address which resources or training experiences were helpful to providers. Information is needed on providers' experience in gathering resources that have assisted in creating effective diagnosis and treatment practices. Additionally, information on education programs or trainings that have been especially helpful to providers in their ability to provide care to patients with MUI/S is needed.

Study characteristics. Many of the articles included in this review contained one or more of the themes outlined above. Although there is variation, providers studied did share some common themes regarding their experiences working with patients presenting with MUI/S. The most prevalent themes found in the reviewed articles were providers' attribution of MUI/S to psychosocial causes (35%; e.g., Asbring & Narvanen, 2003; Cho et al., 2008; Dixon-Woods & Critchley, 2000; refer to Table 3), the idea that MUI/S patients were difficult (27%; e.g., Horton-Salway, 2007; Prins et al., 2000; Raine et al., 2004; refer to Table 3), and providers' lack of confidence with treating patients presenting with MUI/S (30%; e.g., Bowen et al., 2005; Raine et al., 2004; Steven et al., 2000; refer to Table 3).

Along with the variety of themes from each of the articles reported above, the methodology, type of MUI/S, and provider type also varied greatly from article to article. The

most common conditions found in the studies reviewed were CFS/ME (38%), FM (16 %), and medically unexplained symptoms (16%). General practitioners, specialists from a variety of disciplines, and nurse practitioner students were represented in the studies' samples. See Table 2 for a composite description of the participant panels.

Sample sizes in the studies reviewed ranged from three to 811 providers. However, not all researchers reported any detailed participant demographic information (e.g., Bowen et al., 2005; Dixon-Woods & Critchley, 2000; Ho-Yen, 1991; refer to Table 3). Participants from the United Kingdom were represented in 38 percent of the studies reviewed. Participants from the United States were represented in 19 percent of the studies, and the remaining 43 percent were conducted in a variety of countries, such as Sweden (8%) and the Netherlands (8%). Three research teams (Chew-Graham et al., 2008; Cranford & King, 2011; Jason et al., 2001) reported ethnicity statistics for their participants. White providers comprised a majority of the population in each of these three studies. Participants' gender was reported in 54 percent of the studies reviewed. Participants' gender in these studies ranged from about equally male and female, to largely male or largely female. Finally, providers' ages and years of practice were reported in 40 percent and 24 percent of the studies, respectively. Provider ages ranged from 20-73 and provider years of practice ranged from 0-44 years. For further information on study characteristics please reference Table 2.

Surveys/questionnaires were the most popular study methodology found in this group of studies with 51 percent of researchers utilizing this method. Researchers used semi-structured interviews in 35 percent of the studies reviewed, and 11 percent of the studies included the use of focus groups. Researchers in 14 percent of the reviewed studies carried out mixed method research designs utilizing both quantitative and qualitative research methods. Other types of

study designs included case vignettes (Cho et al., 2008) and case descriptions (Scott et al., 1995). Please reference Table 2 for a more detailed representation of study characteristics.

Discussion

The main purposes of this review were to identify, analyze, and report on the qualitative and quantitative research literature regarding medical providers' views of MUI/S and to recommend future studies needed to advance the science behind how medical providers attribute MUI/S and interact with patients toward the development of a mutually satisfying treatment plan. Using attribution theory (Heider, 1958) as a guide, the results of this review indicate that providers attributed a variety of causes to patient expression of MUI/S. Internal, psychosocial attributions (e.g., Asbring & Narvanen, 2003; Hoedeman et al., 2010); external, biomedical attributions (e.g., Kroese et al., 2008; Wainwright et al., 2006), and a combination of psychosocial and biomedical factors (e.g., Gibson & Lindberg, 2011; Philips, 2010) were all reported by providers in this group of studies.

Providers varied in the level of acceptance or skepticism expressed (e.g., Asbring & Narvanen, 2003; Ho-Yen, 1991), diagnoses given (e.g., Steven, et al., 2000), treatment protocols applied (e.g., Cho et al., 2008), and decision-making strategies used (Philips, 2010; Swoboda, 2008). Additionally, provider frustration surrounding work with patients presenting with MUI/S (e.g., Dixon-Woods & Crichley, 2000; Hayes et al., 2010; Hoedman et al., 2010) and lack of confidence in making diagnostic and treatment decisions (e.g., Bowen et al., 2005; Raine et al., 2004; Steven et al., 2000) were themes throughout these studies. Thus, through this review, a general understanding of providers' experience of working with patients with MUI/S has emerged. Even though these studies contribute to a small, but growing, body of knowledge about

providers' experiences surrounding MUI/S, there are numerous gaps in the research that have also emerged from this systematic review.

Gaps and Future Research

Based on the findings in this review, further research is needed to expand our understanding of providers' views of MUI/S and their experience with patients who present with these medical issues. Although MUI/S are commonly seen in primary care, and the cost to both patients and the medical system is great, there is not sufficient information available regarding how providers can increase their level of confidence and decrease their level of frustration when working with patients who present with MUI/S. First, researchers reported on a number of factors that often led to provider frustration when working with MUI/S, such as lack of a definite diagnosis (Chew-Graham et al., 2008) and loss of control in the patient encounter (Hellstrom et al., 1998). However, the reason some providers experienced these negative interactions with patients and some providers found these patients frustrating while others did not is not yet sufficiently understood. Many questions regarding provider levels of frustration have been not been answered in the extant research. For example, which provider characteristics influence the levels of frustration with MUI/S? How do providers' attributions of etiology for MUI/S play a role in the level of difficulty they experience during interactions with patients? What is the role of attribution in the diagnostic and treatment process? How do all of the above impact the providers' experiences of patients with MUI/S as more or less difficult to treat?

Also, since many groups of researchers did not report provider demographic information for their studies (e.g., Bowen et al., 2005; Dixon-Woods & Critchley, 2000; Ho-Yen, 1991) and those who did failed to include comprehensive provider characteristic information (e.g., Fitzgibbon et al., 1997; Prins et al., 2000; Swoboda, 2008), little is known about how different

demographic characteristics impacted providers' experiences of MUI/S. Ethnicity, culture, gender, geographical location, type of setting, provider specialty, and years of practice are some of the provider characteristics that should be analyzed in an attempt to discover whether or not these different population characteristics impact providers' experience of patients with MUI/S, attribution of these medical difficulties, and diagnostic and treatment practices. Again, many questions regarding provider demographic characteristics and their relationship to attribution, frustration, biases, and diagnostic and treatment practices have been left unanswered. Is there a gender difference in diagnostic and treatment practices? Are white providers more likely to be frustrated with MUI/S patients than Asian, Middle-Eastern, Black, or Hispanic providers? Are older providers more likely to attribute MUI/S to internal, psychosocial causes? Does length of time in practice influence diagnostic and treatment decisions?

Additionally, although provider difficulties were discussed, resources, trainings, and further educational opportunities that providers found helpful were largely neglected and were only discussed in one article included in this review (Bieber et al., 2006). Discovering what providers find helpful in their work with MUI/S and uncovering which education programs, if any, have been shown to decrease provider frustration and increase confidence in diagnostic and treatment practices would be greatly helpful. If providers can participate in programs to increase confidence and decrease frustration surrounding MUI/S, they may be more likely to collaborate with patients and their families in the creation of mutually beneficial treatment plans.

Since this field of research is still in its early stages, an attempt to gain depth and breadth of understanding regarding providers' experiences of MUI/S is extremely important. An expanded and more in-depth understanding of the variables that influence providers' experiences of MUI/S could also aid in the development of effective education programs directed at helping

providers to decrease their frustration and to increase their confidence when working with the

MUI/S patient population. In the studies included in this review a majority of the methodologies

used by researchers were either qualitative or quantitative, which typically achieve either breadth

or depth, but generally not both. Mixed methodologies (using both quantitative and qualitative

procedures) were reported in only 14 percent of the studies included in this review. Since

qualitative and quantitative research methods each have different strengths, utilizing mixed

method studies can help to expand and strengthen (Morgan, 1998) what is known about how

providers experience MUI/S.

Also, thus far, the available research on providers' views of MUI/S is from data collected

through qualitative and quantitative self report methods. Since self report studies have a number

of disadvantages, such as potential problems with validity, participants' possible desire to

deceive the researcher, and a propensity of participants not willing to admit socially undesirable

thoughts or behaviors (Barker, Pistrang, & Elliott, 2005), researchers should look to other types

of studies to build the body of literature on providers' views of MUI/S. Creating studies that

collect information through ways other than self-report would be instrumental in gaining a

broader, more multi-faceted view of providers' thoughts, beliefs, and experiences when working

with patients with MUI/S. For example, one such study might involve field observation or

videotaping a sample of providers who attribute MUI/S to varying etiologies. Observations of

providers meeting patients identified as having MUI/S may help to discover what, if any, impact

attribution has on patient/provider interactions and each person's satisfaction with the

appointment and treatment outcomes.

Future research may also benefit from utilizing information found in case studies, book

chapters, and articles that do not include original research. In order to maintain the degree of

rigor necessary for this systematic review, we were unable to incorporate findings from these additional sources. However, in addition to the utilization of mixed methods study designs, information-rich resources such as case studies could possibly expand and give depth to the overall understanding of providers' perspectives of MUI/S.

There is not an existing model that explains why providers may be frustrated or may have a difficult time interacting with patients identified as having MUI/S (e.g., Chew-Graham et al., 2008). Using designs that incorporate structural equation modeling (Ullman, 2006), researchers may be able to generate a model that can identify the relationships between factors such as provider attribution, diagnostic and treatment practices, frustration, satisfaction with the patient/provider relationship, diagnosis and treatment outcomes, and healthcare costs. If we ultimately hope to understand providers' experiences of working with patients with this group of medical difficulties, as well as to train and support them, it is instrumental that we come up with a comprehensive model to define the factors that determine providers' attribution and experience surrounding their work with this patient population.

Further, any comprehensive model that allows for greater understanding of how to treat patients with MUI/S also will need to include factors beyond a solely biomedical understanding of patients' symptoms. Creating an expansive model that [includes provider awareness of the consequences of their own attributions and assists them in attending to the interplay between psychosocial and biomedical factors may lend itself to a broader picture of patients presenting with MUI/S, which can, in turn, allow providers to practice more patient-centered care.

REFERENCES

*Asbring, P., & Narvanen, A. L. (2003). Ideal versus reality: Physicians perspectives on patients with chronic fatigue syndrome (CFS) and fibromyalgia. *Social Science & Medicine*, 57, 711-720. doi:10.1016/S0277-9536(02)00420-3

Barker, C., Pistrang, N., Elliott, R. (2005). *Research methods in clinical psychology: An introduction for students and practitioners* (2nd ed.). Chester, UK: Wiley. doi:10.1002/0470013435

*Bieber, C., Muller, K. G., Blumenstiel, K., Schneider, A., Richter, A., Wilke, S., … Eich, W. (2006). Long-term effects of a shared decision-making intervention on physician-patient interaction and outcome in fibromyalgia. A qualitative and quantitative 1 year follow-up of a randomized controlled trial. *Patient Education and Counseling*, *63*, 357-366. doi:10.1016/j.pec.2006.05.003

Borkowski, N. M., & Allen, W. R. (2003). Does attribution theory explain physicians' non acceptance of clinical practice guidelines? *Hospital Topics, 81*(2), 9-21.

*Bowen, J., Pheby, D., Charlett, A., & McNulty, C. (2005). Chronic fatigue syndrome: A survey of GPs' attitudes and knowledge. *Family Practice Advance Access*, 22, 389-393. doi:10.1186/147-2296-6-49

Burton, C., McGorm, K., Richardson, G., Weller, D., & Sharpe, M. (2012). Healthcare costs incurred by patients repeatedly referred to secondary medical care with medically unexplained symptoms: A cost of illness study. *Journal of Psychosomatic Research, 72*, 242-247. doi:10.1038/jid.2012.12

*Chew-Graham, C. A., Cahill, G., Dowrick, C., Wearden, A., & Peters, S. (2008). Using multiple sources of knowledge to reach clinical understanding of chronic fatigue

syndrome. *Annals of Family Medicine, 6*(4), 340-348. doi:10.1370/afm.867

*Cho, H. J., Menezes, P. R., Bhugra, D., & Wessely, S. (2008). The awareness of chronic fatigue

syndrome: A comparative study in Brazil and the United Kingdom. *Journal of*

Psychosomatic Research, 64, 351-355. doi:10.1016/j.jpsychores.2007.12.006

Cobb, M., & DeChabert, J. T. (2002). HIV/AIDS and care provider attributions: Who's to

blame? *AIDS Care, 14*(4), 545-548. doi:10.1080/09540120220133062

Cooper, H. M. (2010). *Research synthesis and meta-analysis: A step-by-step approach* (4th ed.).

Washington, DC: Sage.

*Cranford, C., & King, C. R. (2011). Nurse practitioner students' perceptions of fibromyalgia

pain and quality of life. *Medsurg Nursing, 20*(4), 169-177.

*Denz-Penhey, H., & Murdoch, J. C. (1993). General practitioners acceptance of the validity of

chronic fatigue syndrome as a diagnosis. *New Zealand Medical Journal, 106*(953), 122-

124.

*Dixon-Woods, M., & Critchley, S. (2000). Medical and lay views of irritable bowel syndrome.

Family Practice, 17(2), 108-113. doi: 10.1093/fampra/17.2.108

Dumit, J. (2005). Illnesses you have to fight to get: Facts as forces in uncertain,

emergent illnesses. *Social Science & Medicine, 62*, 577-590.

doi:10.1016/j.socscimed.2005.06.018

Edelson, S. & Statman, J. (1998). *Living with environmental illness: A practical guide to*

multiple chemical sensitivity. Dallas, TX: Taylor Publishing Company

Edwards, T. M., Stern, A., Clarke, D. D., Ivbijaro, G., & Kasney, L. M. (2010). The treatment of

patients with medically unexplained symptoms in primary care: A review of the

literature. *Mental Health in Family Medicine, 7*, 209-221.

*Fitzgibbon, E. J., Murphy, D., O'Shea, K., & Kelleher, C. (1997). Chronic debilitating fatigue in Irish general practice: A survey of general practitioners' experience. *British Journal of General Practice, 47*, 618-622.

Gibson, P. R. (2006). *Multiple chemical sensitivity: A survival guide*. Churchville, VA: Earthrive Books.

*Gibson, P. R., & Lindberg, A. (2011). Physicians' perceptions and practices regarding patient reports of multiple chemical sensitivity. *International Scholarly Research Network*. Retrieved from http://downloads.ism.com/journals/nursing/2011/838930.pdf. doi:10.5402/2011/838930

*Gomez, R. L., Schvaneveldt, R. W., & Staudenmayer, H. (1996). Assessing beliefs about environmental illness/multiple chemical sensitivity. *Journal of Health Psychology, 1*(1), 107-123. doi:10.1177/135910539600100109

*Hartman, T. C., Hassink-Franke, L. J., Lucassen, P. L., van Spaendonck, K. P., & van Weel, C. (2009). Explanation and relations. How do general practitioners deal with patients with persistent medically unexplained symptoms: A focus group study. *BMC Family Practice, 10*(68). Retrieved from http://www.biomedcentral.com/1471-2296/10/68/. doi:10.1186/1471-2296-10-68

*Hartz, A. J., Noyes, R., Bentler, S. E., Damiano, P. C., Willard, J. C., & Momany, E. T., (2000). Unexplained symptoms in primary care: Perspectives of doctors and patients. *General Hospital Psychiatry, 22*, 144-152. doi:10.1016/S0163-8343(00)00060-8

*Hayes, S. M., Myhal, G., Thorton, J. F., Camerlain, M., Jamison, C., Cytryn, K. N., & Murray, S. (2010). Fibromyalgia and the therapeutic relationship: Where uncertainty meets attitude. *Pain Resource Management, 15*(6), 385-291.

Heider, F. (1958). *The psychology of interpersonal relations*. New York, NY: Wiley.

*Hellström, O., Bullington, J., Karlsson, G., Lindqvist, P., & Mattsson, B. (1998). Doctors'
    attitudes to fibromyalgia: a phenomenological study. *Scandinavian Journal of Social
    Medicine*, *26*(3), 232-237. doi:10.1080/14034949850153545

*Hoedeman, R., Krol, B., Blankenstein, A. H., Koopmans, P. C., & Groothoff, J. W. (2010).
    Sick-listed employees with severe medically unexplained physical symptoms: Burden or
    routine for the occupational health physician? A cross sectional study. *BMC Health
    Services Research, 10*, 305-312. doi:10.1186/1472-6963-10-305

*Ho-Yen, D. O. (1991). General practitioners' experience of the chronic fatigue syndrome.
    British Journal of General Practice, 41, 324-326.

*Horton, S., Poland, F., Kale, S., de Lourdes Drachler, M., de Caralho Leite, J. C.,… Nacul, L.
    (2010). Chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) in adults: A
    qualitative study of perspectives from professional practice. *BMC Family Practice,
    11*(89). doi:10.1186/1471-2296-11-89

*Horton-Salway, M. (2007). The 'ME Bandwagon' and other labels: Constructing the genuine
    case in talk about a controversial illness. *British Journal of Social Psychology, 46*, 895-
    914. doi:10.1348/014466607X173456

*Jason, L. A., Taylor, R. R., & Stepnek, Z. (2001). Attitudes regarding chronic fatigue
    syndrome: The importance of a name. *Journal of Health Psychology, 6*(1), 61-71.
    doi:10.1177/135910530100600105

Johnson, S. K. (2010). *Medically unexplained illness: Gender and biopsychosocial implications*.
    Washington, DC: American Psychological Association. doi:10.1037/11623-000

Jones, E. E., Kanouse, D. E., Kelley, H. H., Nisbett, R. E., , Valins, S., & Weiner, B. (Eds).

(1972). *Attribution: Perceiving the causes of behavior*. Morristown, NJ: General

Learning.

Kelley, H. H., (1960). The analysis of common sense. A review of "The psychology of

interpersonal relations" by Fritz Heider. *Contemporary Psychology, 5*, 1-3.

Kilshaw, S. (2008). Gulf war syndrome: A reaction to psychiatry's invasion of the military.

Cultural and Medical Psychiatry, 32, 219-237. doi:10.1007/s11013-008-9088-0

*Kroese, M. L., Schulpen, G. C., Sonneveld, H. M., & Vrijhoef, H. M. (2008). Therapeutic

approaches to fibromyalgia in the Netherlands: A comparison between 1998 and

2005. *Journal of Evaluation in Clinical Practice*, *14*(2), 321-325. doi:10.1111/j.1365-

2753.2007.00862.x

*Lundh, C., Segesten, K., & Bjorkelund, C. (2004). To be a helpless helpoholic – GPs'

experiences of women patients with non-specific muscular pain. *Scandinavian Journal of

Primary Health Care, 22,* 244-247. doi:10.1080/02813430410006756

Madden, S. & Sim, J. (2006). Creating meaning in fibromyalgia syndrome. *Social Science &

Medicine, 63*(11), 2962-2973. doi:10.1016/j.socscimed.2006.06.020

Martinko, M. J., Harvey, P., & Douglas, S. C. (2007). The role, function, and contribution of

attribution theory to leadership: A review. *The Leadership Quarterly, 18*, 561-585.

doi:10.1016/j.leaqua.2007.09.004

Morgan, D. L. (1998). Practical strategies for combining qualitative and quantitative methods:

Applications to health research. *Qualitative Health Research, 8*, 362-376.

doi:10.1177/104973239800800307

Mosher, C. E., & Danoff-Burg, S. (2008). An attributional analysis of gender and cancer-related

stigma. *Sex Roles 59*, 827-838. doi:10.1007/s11199-008-9487-2

Nettleton, S. (2006). 'I just want permission to be ill': Towards a sociology of medically
unexplained symptoms. *Social Science & Medicine, 62(*5), 1167-1178.
doi:10.1016/j.socscimed.2005.07.030

*Phillips, T. (2010). Debating the legitimacy of a contested environmental illness: A case study
of multiple chemical sensitivities (MCS). *Sociology of Health & Illness, 32*(7), 1026-
1040. doi:10.1111/j.1467-9566.2010.01255.x

*Prins, J. B., Bleijenberg, G., Rouweler, E. K., van Weel, C., & van der Meer, J. W. M. (2000).
Doctor-patient relationship in primary care of chronic fatigue syndrome: Perspectives of
the doctor and the patient. *Journal of Chronic Fatigue Syndrome, 7*(4), 3-15.

*Raine, R., Carter, S., Sensky, T., & Black, N. (2004). General practitioners' perceptions of
chronic fatigue syndrome and beliefs about its management, compared with irritable
bowel syndrome: Qualitative study. *British Medical Journal*, 328, 1354-1356.
doi:10.1136/bmj.38078.503819.EE

Reid, S., Wessely, S., Crayford, T., & Hotopf, M. (2002). Frequent attenders with medically
unexplained symptoms: Service use and costs in secondary care. *British Journal of
Psychiatry, 100*, 248-253. doi:10.1192/bjp.180.3.248

*Reid, S., Whooley, D., Crayford, T., & Hotopf, M. (2001). Medically unexplained
symptoms- GPs' attitude toward their cause and management. *Family Practice,
18*(5), 519-523. doi:10.1093/fampra/18.5.519

*Richardson, R. D., Engel, C. C., McFall, M., McKnight, K., Boehnlein, J. K., & Hunt, S. C.
(2001). Clinician attributions for symptoms and treatment of Gulf War-related health
concerns. *Archives of Internal Medicine*, 161, 1289-1294.
doi:10.1001/archinte.161.10.1289

*Salmon, P., Ring, A., Dorwrick, C. F., Humphris, G. M. (2005). What do general practice patients want when they present medically unexplained symptoms, and why do their doctors feel pressurized? *Journal of Psychosomatic Research, 59*, 255-262. doi:10.1016/j.jpsychores.2005.03.004

*Scott, S., Deary, I., & Pelosi, A. J. (1995). General practitioners' attitudes to patients with a self diagnosis of myalgic encephalomyelitis. *British Medical Journal, 310*, 508. doi:10.1136/bmj.310.6978.508

*Sharpe, M., Mayou, R., Seagroatt, V., Surawy, C., Warwick, H., Bulstrode, C., Dawber, R., & Lane, D. (1994). Why do doctors find some patients difficult to help? *Quarterly Journal of Medicine, 87*, 187-193.

*Skovbjerg, S., Johansen, J., Rasmussen, A., Thorsen, H., & Elberling, J. (2009). General practitioners' experiences with provision of healthcare to patients with self-reported multiple chemical sensitivity. *Scandinavian Journal of Primary Health Care*, *27*(3), 148-152. doi:10.1080/02813430902888355

*Steven, I. D., McGrath, B., Qureshi, F., Wong, C., Chern, I., & Pearn-Rowe, B. (2000). General practitioners' beliefs, attitudes and reported actions towards chronic fatigue syndrome. *Australian Family Physician, 29*, 80-85.

Switzer, B. A., & Boysen, G. (2009). The impact of religiosity and attribution theory on attitudes toward addiction and cancer. *Mental Health, Religion & Culture, 12*(3), 241-245. doi:10.1080/13674670802428449

*Swoboda, D. A. (2008). Negotiating the diagnostic uncertainty of contested illnesses: Physician practices and paradigms. *Health: An Interdisciplinary Journal for the*

Social Study of Health, Illness, and Medicine, 12(4), 453-478.

doi:10.1177/1363459308094420

*Thomas, M. A., & Smith, A. P. (2005). Primary healthcare provision and chronic fatigue

syndrome: A survey of patients' and general practitioners' beliefs. *BMC Family Practice,*

49(6). Retrieved from http://www.biomedcentral.com/1471-2296/6/49/.

doi:10.1186/1471-2296-6-49

Ullman, J. B. (2006). Structural equation modeling: Reviewing the basics and moving forward.

Journal of Personality Assessment, 87(1), 35-50. doi:10.1207/s15327752jpa8701_03

*Wainwright, D., Calnan, M., O'Niel, C., Winterbottom, A., & Watkins, C. (2006). When pain

in the arm is 'all in the head': The management of medically unexplained suffering in

primary care. *Health, Risk & Society, 8*(1), 71-88. doi:10.1080/13698570500532512

Weary, G., Rich, M. C., Harvey, J. H., & Ickes, W. J. (1980). Heider's formulation of social

perception and attribution processes: Toward further clarification. *Personality and Social*

*Psychology Bulletin, 37(*6), 37-43. doi:10.1177/014616728061005

Weiner, B. (1979). A theory of motivation for some classroom experiences. *Journal of*

Educational Psychology, 71, 3-25. doi:10.1037//0022-0663.71.1.3

Weiner, B. (2008). Reflections on the history of attribution theory and research: People,

personalities, publications, problems. *Social Psychology, 39*(3), 151-156.

Werner, A. & Malterud, K. (2003). It is hard work behaving as a credible patient: Encounters

between women with chronic pain and their doctors. *Social Science & Medicine, 57*(8),

1409-1419. doi:10.1016/S0277-9536(02)00520-8

*Wileman, L., May, C., & Chew-Graham, C. A. (2002). Medically unexplained symptoms and

the problem of power in the primary care consultation: A qualitative study. *Family*

Practice, 19(2), 178-182. doi:10.1093/fampra/19.2.178

* Article included in systematic review

Table 1
Review Search Strategy

PsychoInfo via Pubmed	Medline Collection	Biomedical Reference	OVID/PsychArticles
Unexplained illness and provider Yield: 14 Found: 1	Unexplained illness and provider Yield: 8 Found: 0	Unexplained illness and provider Yield: 2 Found: 0	Unexplained illness and provider Yield: 0 Found: 0
Unexplained illness and doctor Yield: 27 Found: 3	Unexplained illness and doctor Yield: 98 Found: 3	Unexplained illness and doctor Yield: 8 Found: 0	Unexplained illness and doctor Yield: 0 Found: 0
Unexplained illness and physician Yield: 59 Found: 3	Unexplained illness and physician Yield: 143 Found: 4	Unexplained illness and physician Yield: 23 Found: 0	Unexplained illness and physician Yield: 0 Found: 0
Contested illness and provider Yield: 6 Found: 0	Contested illness and provider Yield: 1 Found: 0	Contested illness and provider Yield: 2 Found: 0	Contested illness and provider Yield: 0 Found: 0
Contested illness and doctor Yield: 8 Found: 1	Contested illness and doctor Yield: 13 Found: 1	Contested illness and doctor Yield: 6 Found: 0	Contested illness and doctor Yield: 0 Found: 0
Contested illness and physician Yield: 13 Found: 1	Contested illness and physician Yield: 15 Found: 1	Contested illness and physician Yield: 11 Found: 0	Contested illness and physician Yield: 0 Found: 0
Unexplained illness and doctor-patient Yield: 5 Found: 2	Unexplained illness and doctor-patient Yield: 6 Found: 1	Unexplained illness and doctor-patient Yield: 2 Found: 0	Unexplained illness and doctor-patient Yield: 0 Found: 0
Contested illness and doctor-patient Yield: 2 Found: 0	Contested illness and doctor-patient Yield: 1 Found: 0	Contested illness and doctor-patient Yield: 2 Found: 0	Contested illness and doctor-patient Yield: 0 Found: 0
Provider and fibromyalgia Yield: 31 Found: 0	Provider and fibromyalgia Yield: 25 Found: 2	Provider and fibromyalgia Yield: 8 Found: 0	Provider and fibromyalgia Yield: 2 Found: 0
Provider and chronic fatigue Yield: 42 Found: 0	Provider and chronic fatigue Yield: 33 Found: 0	Provider and chronic fatigue Yield: 19 Found: 0	Provider and chronic fatigue Yield: 3 Found: 0
Provider and	Provider and	Provider and	Provider and

environmental illness Yield: 79 Found: 0	environmental illness Yield: 31 Found: 0	environmental illness Yield: 19 Found: 0	environmental illness Yield: 0 Found: 0
Provider and chemical sensitivity Yield: 6 Found: 0	Provider and chemical sensitivity Yield: 5 Found: 0	Provider and chemical sensitivity Yield: 6 Found: 0	Provider and chemical sensitivity Yield: 0 Found: 0
Provider and gulf war syndrome Yield: 0 Found: 0	Provider and gulf war syndrome Yield: 2 Found: 0	Provider and gulf war syndrome Yield: 1 Found: 0	Provider and gulf war syndrome Yield: 0 Found: 0
Doctor and chemical sensitivity Yield: 5 Found: 1	Doctor and chemical sensitivity Yield: 96 Found: 2	Doctor and chemical sensitivity Yield: 7 Found: 0	Doctor and chemical sensitivity Yield: 0 Found: 0
Doctor and fibromyalgia Yield: 24 Found: 1	Doctor and fibromyalgia Yield: 244 Found: 7	Doctor and fibromyalgia Yield: 7 Found: 1	Doctor and fibromyalgia Yield: 1 Found: 0
Doctor and chronic fatigue Yield: 64 Found: 3	Doctor and chronic fatigue Yield: 343 Found: 3	Doctor and chronic fatigue Yield: 67 Found: 1	Doctor and chronic fatigue Yield: 1 Found: 0
Doctor and gulf war syndrome Yield: 5 Found: 2	Doctor and gulf war syndrome Yield: 14 Found: 1	Doctor and gulf war syndrome Yield: 7 Found: 0	Doctor and gulf war syndrome Yield: 1 Found: 0
Doctor and environmental illness Yield: 43 Found: 1	Doctor and environmental illness Yield: 319 Found: 0	Doctor and environmental illness Yield: 20 Found: 0	Doctor and environmental illness Yield: 0 Found: 0
Physician and fibromyalgia Yield: 124 Found: 0	Physician and fibromyalgia Yield: 406 Found: 1	Physician and fibromyalgia Yield: 40 Found: 2	Physician and fibromyalgia Yield: 7 Found: 0
Physician and chronic fatigue Yield: 153 Found: 3	Physician and chronic fatigue Yield: 500 Found: 0	Physician and chronic fatigue Yield: 95 Found: 0	Physician and chronic fatigue Yield: 4 Found: 0
Physician and environmental illness Yield: 143 Found: 1	Physician and environmental illness Yield: 454 Found: 0	Physician and environmental illness Yield: 106 Found: 0	Physician and environmental illness Yield: 0 Found: 0
Physician and	Physician and	Physician and	Physician and

chemical sensitivity Yield: 18 Found: 2	chemical sensitivity Yield: 124 Found: 0	chemical sensitivity Yield: 15 Found: 0	chemical sensitivity Yield: 0 Found: 0
Physician and gulf war syndrome Yield: 5 Found: 1	Physician and gulf war syndrome Yield: 24 Found: 0	Physician and gulf war syndrome Yield: 6 Found: 0	Physician and gulf war syndrome Yield: 1 Found: 0
Total: 18 of 876 Duplicates Removed: 8	Total: 12 of 2,896 Duplicates Removed: 26	Total: 4 of 479 Duplicates Removed: 1	Total: 0 of 20 Duplicates Removed: 0

Figure 1. Search Methodology.


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┌─────────────────────────────┐
│     Key words searched      │
└─────────────────────────────┘
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PsychInfo (n=876)

Medline via Pubmed (n=2,896)
Biomedical Reference Collection (n=479)

Ovid/PsychArticles (n=20)

Title and Abstract Check

Total selected to verify if met inclusion criteria (n=34)

Applied inclusion criteria and performed citation tracking of the 34 articles

Citation tracking resulted in additional articles added to the review (n=13)

Applied inclusion criteria and performed citation tracking of the 13 articles

Citation tracking resulted in additional articles added to the review (n=2)

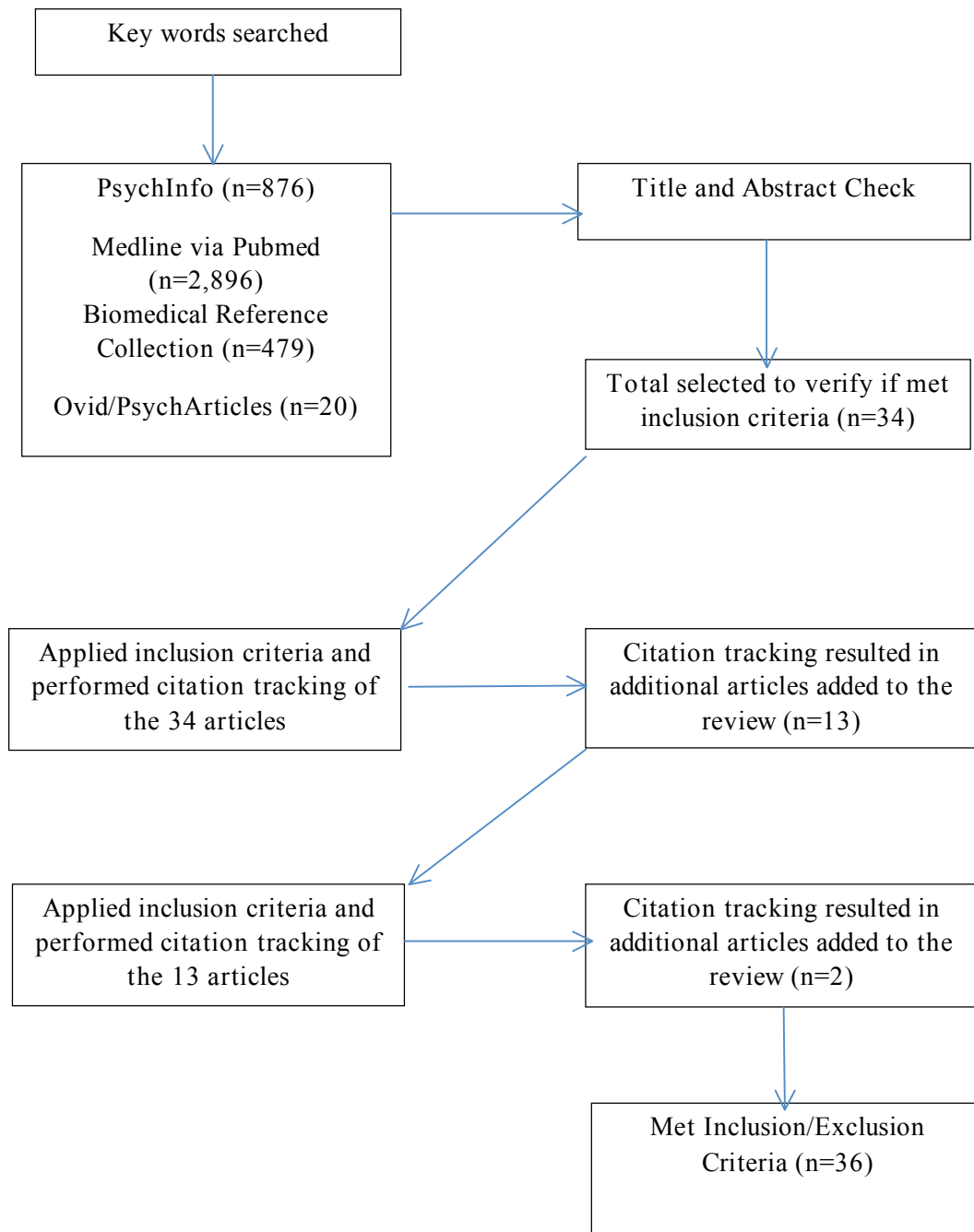Met Inclusion/Exclusion Criteria (n=36)

Table 2

Study Characteristics

Authors	Condition Studied	Medical Providers Included in the Study	Study Design Related to Provider Perceptions	Main Findings Related to Provider Perceptions
Asbring & Narvanen, 2003	Chronic Fatigue Syndrome & Fibromyalgia	Provider Type: 26 physicians; general practitioners and specialists Gender: 14 men, 12 women Age: m= 50 range= 41-67 Location: Sweden	Semi-structured interviews	• Physicians expressed skepticism regarding CFS and FM. • Patient credibility was questioned • The physician role was challenged by CFS and FM. • Several physicians described psychological reasons for these illnesses.
Bieber et al., 2006	Fibromyalgia	Provider Type: 13 internal medicine specialists Gender: 50% female Age: m= 30.7 Location: Germany	Semi-structured interviews and surveys completed by 13 physicians	• Physicians who participated in a shared decision making group reported less difficult interactions with patients and had less negative feelings about their patients than physicians in an information group.
Bowen et al., 2005	Chronic Fatigue Syndrome	Provider Type: 811 general practitioners Location: United Kingdom	Questionnaires	• Confidence making a diagnosis and managing CFS among GPs was low. • 28% of GPs did not accept CFS as recognizable diagnosis. • Accepting CFS as a diagnosis, knowing someone socially with CFS, and being male were correlated with positive attitudes toward CFS.
Chew-Graham et al., 2008	Chronic Fatigue Syndrome	Provider Type: 44 family physicians Gender: 7 males,	In-depth semi-structured interviews	• Physicians believed they were not prepared to manage and diagnose

		7 females Age: 26-63 years old Ethnicity: 9 White, 2 Black, 3 Asian Location: England		CFS by their medical training. • Doubt about the diagnosis led to physician frustration, which impacted the doctor-patient relationship. • Physicians attempted to access knowledge about CFS through media, observations of patients outside the patient exam, and through personal experience.
Cho et al., 2008	Chronic Fatigue Syndrome	Provider Type: 120 Brazilian specialist doctors; varying specialties Gender: 52.5% female Age: 24-60 mean 34.5 Years of Practice: 10.1 years since graduation Location: Brazil	Case vignettes	• Only 30% of Brazilian doctors recognized CFS, which is much lower than doctors in western countries. • The cause most frequently mentioned for CFS case vignette was stress/overworking or psychological problems. • Treatment most frequently indicated was antidepressants, exercise therapy, and counseling.
Cranford & King, 2011	Fibromyalgia	Provider Type: 21 nurse practitioner students Gender: 95% female Age: 33 average age Years of Practice: 8.5 years average practice as registered nurses Ethnicity: 86% Caucasian Location: United States	Survey with both quantitative and qualitative questions	• NP students believed FMS affected all aspects of a person's life and believed they were prepared to treat QOL issues more than FM pain. • Skepticism about FMS exists within this sample. • Desired to improve knowledge about patient's experience with FM.
Denz-	Chronic	Provider Type: 83	Questionnaire	• 69% of general

Penhey & Murdoch, 1993	Fatigue Syndrome	general practitioners Location: New Zealand		practitioners felt they had sufficient knowledge to make a CFS diagnosis. • 90% of general practitioners accepted the validity of CFS as a clinical diagnosis.
Dixon-Woods & Critchley, 2000	Irritable Bowel Syndrome	Provider Type: 12 doctors, 6 GPs, 6 gastroenterologist Location: United Kingdom	In-depth semi-structured interviews	• Stress and psychological factors emphasized by medical providers as cause of IBS. • Providers view IBS by drawing on their own experiential knowledge and prejudices in private definitions about the condition. • IBS was source of frustration for may providers and may be fueled by absence of effective treatment and poor medical understanding of IBS.
Fitzgibbon et al., 1997	Chronic debilitating fatigue	Provider Type: 200 doctors Gender: 30 women (27% over 45) 88 men (42% over 45) Location: Ireland	Questionnaires	• The term CFS is as likely to evoke skepticism as sympathy. • Doctors differ considerably in treatment strategies. • Many doctors are unsatisfied with the quality of care they provide to patients with CFS. • Only slightly more than half of the doctors surveyed accepted CFS as a distinct clinical entity and many lacked the confidence to make a CFS diagnosis.
Gibson & Lindberg,	Multiple Chemical	Provider Type: 90 physicians from	Surveys	• Physicians gained MCS knowledge through

2011	Sensitivity	26 specialties Years of Practice: Mean of 15.5 Location: Virginia, United States		many different sources. • The majority of physicians were either unsatisfied or somewhat satisfied with knowledge of MCS. • Most believed MCS etiology was combination of psychological and medical. • 97% reported they have had patients with chemical sensitivity but only 6% had a treatment protocol for the condition.
Gomez et al, 1996	Multiple Chemical Sensitivity	Provider Type: 11 doctors specializing in allergy and immunology Gender: 10 male, 1 female Age: 38-72 years old Location: United States	Questionnaires ranking concepts related to MCS	• Allergists related MCS to emotional upset or stress response. • Physicians must discriminate between disorder of belief and real disease processes when presented with multi system complaints related to chemical exposure.
Hartman et al., 2009	Medically unexplained symptoms	Provider Type: 22 general practitioners Gender: 14 male, 8 female Age: 31-58 years old – mean age 47 Years of Experience: 0-30 - mean experience 15 years Location: Netherlands	Focus groups	• GPs recognize limitations and difficulties in establishing effective relationship with MUS patients and take the responsibility to build such relationships. • GPs described three different models to maintain relationships with MUS patients.
Hartz et al., 2000	Unexplained Symptoms	Provider Type: 259 general practitioners Place of Practice:	Surveys	• Only 25% of providers rated their experience helping patients with unexplained illness as

		50% urban practice, 50% suburban practice Location: Iowa, United States		very good or excellent. • Only 14% of providers were satisfied with their ability to help patients with unexplained illness. • Providers had unmet needs surrounding their ability to manage patients with unexplained illness.
Hayes et al., 2010	Fibromyalgia	Provider Type: 189 general practitioners, 139 specialists, 2 nurses Gender: 73% male, 27% female Place of Practice: 72% urban practice, 13% suburban practice Location: Canada practitioners, 139 specialists, 2 nurses	Discussion groups, semi-structured interviews, online surveys	• Many participants described FM as time consuming and frustrating. • FM was characterized by undefined criteria for treatment, a need for support and interventions that physicians felt ill equipped to provide, and mismatched perceptions and unmet needs on parts of both patients and physicians in treating FM.
Hellstrom et al., 1998	Fibromyalgia	Provider Type: 10 rheumatologists Gender: 5 men, 5 women Age: 31-58 years of age Years of Experience: 5-22 years of experience, 16 average years of professional experience and 10 average years with rheumatology specialty Location: Sweden	Interviews	• Doctors dislike situations in which they do not feel in control. • Doctors relied on biomedical knowledge and view of patient's illness, which could be managed by their acquired knowledge. • Doctors stressed importance of good communication, which could lead to a good patient-provider relationship.
Hoedeman	Medically	Provider Type: 43	Questionnaires	• A majority of OHPs

et al., 2010	unexplained physical symptoms	occupational health physicians Gender: 54.8% female Age: mean age 46.5 Years of Experience: 12.2 years of work experience 83.7 % working full time Place of Practice: physicians from both urban and rural areas Location: Netherlands		searched for psychosocial explanations for symptoms. • They only experienced difficulties working with MUPS patients when they had to communicate with the patient's physician. • A lack of treatment tasks for OHPs was discussed as the possible reason for their lack of frustration with MUPS patients.
Ho-Yen, 1991	Chronic Fatigue Syndrome	Provider Type: 178 general practitioners Location: United Kingdom	Questionnaires	• 77% of GPs accepted existence of CFS. • GPs thought some patients with CFS took excessive amounts of their time while others took only average amounts of time. • Single-handed provider practices had lowest rate of acceptance of CFS.
Horton et al., 2010	Chronic Fatigue Syndrome	Provider Type: 6 doctors, 3 specialists and 3 general practitioners Location: England	Semi-structured interviews	• Reaching a diagnosis can be challenging when providers have little experience with CFS. • Providers expressed frequent uncertainty regarding the condition. • Some providers still deny the existence of CFS as a condition • Listening and building trustful relationship is a vital role for providers.
Horton-Salway, 2007	Chronic Fatigue Syndrome/	Provider Type: 10 general practitioners	Semi-structured interviews	• GPs believe ME has a psychological cause and that patients seek a

	ME	Location: United Kingdom		medical label for 'every day' problems. • GPs believe patients use ME label to avoid fixing their lives and think they have ME because they are persuaded by what they read and hear in the media. • Its difficult for GPs to police boundary between genuine sufferers and 'bandwagon' patients.
Jason et al., 2001	Chronic Fatigue Syndrome/ ME	Provider Type: 105 medical trainees Gender: 45% female, 55% male Age: 61% ages 20-29, 29% ages 30+ Ethnicity: 33% European American, 8% Latino(a) American, 11% African American, 26% East Asian/Indian, 19% Asian American, 3% Other Location: Chicago, Illinois, United States	Vignettes	• The name CFS or ME garnered different attributions for causation. • ME was attributed to biomedical cause while CFS was attributed to psychiatric factors.
Kroese et al., 2008	Fibromyalgia	Provider Type: Two samples: 1998 and 2005 1998: 320 general practitioners and specialists 2005: 303 general practitioners and specialists	Questionnaire	• Recommended therapies are not commonly applied. • Biomedical and psychosocial treatments are used. • FM patients are referred to different types of providers involved in the

		Location: Netherlands		management of FM. • The choice of treatment is subjective and based on provider's experiences.
Lundh et al., 2004	Non-specific muscular pain	Provider Type: 14 general practitioners Gender: 8 women, 6 men from low and high socioeconomic areas Age: 35-60 years of age Location: Sweden	Focus groups	• Neither the biomedical nor the psychosocial paradigm helped GPs understand patient problems • GPs perceived patients as wanting biomedical explanations for their problems. • GPs used creativity and energy to try to understand the origin of patient complaints and became frustrated, irritated, and agitated when they did not have adequate tools to help patients.
Phillips, 2010	Multiple Chemical Sensitivity	Provider Type: 8 medical specialists Location: Australia	Interviews	• There are three main approaches to understand and treat MCS between participants. • Skeptics and supportive medical professionals used inductive reasoning strategies but they approached uncertainty differently. • Both skeptics and supportive professionals believed MCS is a combination of psychological, physiological, and emotional factors.
Prins et al., 2000	Chronic Fatigue Syndrome	Provider Type: 121 general practitioners Years of	Questionnaires and interviews	• More than half of GPs sympathized less with CFS patients than other patients and those who

		Experience: 1-28 years of professional experience, mean of 11.5 years Location: Netherlands		did not sympathize had more difficulty communicating with CFS patients. • The majority of GPs attributed CFS to psychosocial factors. • Only 10% felt capable of giving sufficient information to CFS patients. • The majority felt CFS patients took more time, and reported problems with communication and rated cooperation as 'bad.'
Raine et al., 2004	Chronic Fatigue Syndrome and Irritable Bowel Syndrome	Provider Type: 46 general practitioners Gender: 29 men, 37 white Age: 46.9 mean age Years of Experience: 14.8 average years in general practice Location: England	Qualitative analysis of transcripts of group discussions	• GPs stereotyped patients with CFS as having undesirable traits, which did not occur with patients with IBS. • GPs reported conflicts with CFS patients about causes treatment options. • GPs felt choosing treatments for CFS was like 'groping in the dark' and described caring for CFS patients as a burden.
Reid et al., 2001	Medically unexplained symptoms	Provider Type: 284 general practitioners Gender: 60.4% male Age: mean age 43.9 range 29-73 Years of Experience: 13.2 years mean time spent working – range 1-44 Location: United Kingdom	Questionnaires	• 93% found it difficult to manage patients with MUS, 63.3 percent believed these patients have a psychiatric illness, and 74% disagree that these patients have an undiagnosed physical illness. • Psychological problems were thought to be the major contributor to MUS.

				• GPs thought management strategies for MUS were lacking.
Richardson et al., 2001	Gulf War-related health concerns	Provider Type: 77 general internal medicine clinicians, 214 mental health clinicians Location: Seattle, Washington, United States	Survey	• Clinicians evoke explanations outside their scope of knowledge when faced with uncertainty. • Clinicians defer to providers within other disciplines who might have new information and can provide new treatment recommendations. • MH providers were more likely to believe GWS resulted from biomedical causes while GIMCs were more likely to believe GWS resulted from psychosocial difficulties. • Almost half of medical and MH providers believed symptoms resulted from a combination of mental and physical disorders.
Salmon et al., 2005	Medically unexplained symptoms	Provider Type: 42 general practitioners Gender: 22 male, 20 female Age: 5-42 years of experience Practice Type: 6 practices urban, 4 practices suburban, 1 practice rural Location: United Kingdom	Cross-sectional comparison of case-matched groups	• Some GPs experienced MUS patients as more controlling while many experienced no difference. • GPs experience of patient influence was related to how much emotional support they perceived patients wanted.
Scott et al., 1995	Myalgic Encephalo-	Provider Type: 132 general	Case descriptions	• Self diagnosis led GPs to think patients would be

	myelitis	practitioners Location: Scotland		less likely to comply with treatment and more likely to take up time and pose difficulties.
Sharpe et al., 1994	"difficult to help" patients	Provider Type: 3 specialists: orthopedics, respiratory medicine, dermatology Location: United Kingdom	Interviews and rating scales	• Absence of diagnosis that would explain symptoms and failure of treatments to relieve symptoms were most commonly associated with patient difficulty ratings. • Doctors rarely disliked patients but felt frustrated, inadequate, or helpless when they cared for patients that were difficult. • Doctors saw a role for psychological care for more than 50% of difficult patients.
Skovbjerg et al., 2009	Multiple Chemical Sensitivity	Provider Type: 691 general practitioners Gender: 37.9% women Age: 15.4 average years of experience Location: Denmark	Questionnaire	• 42% of GPS reported they were rarely able to meet patient expectations. • 64.3% believed symptoms were multi-factorial. • The majority requested more knowledge about MCS and diagnostic tools.
Steven, et al., 2000	Chronic Fatigue Syndrome	Provider Type: 1,615 general practitioners Gender: 1190 (74%) male, 419 (26%) female Age: 16% 34 or under 38 % 35-44 25% 45-54 21% 55+ Employment	Survey	• GPs had a variety of beliefs about diagnosis and management practices for CFS. • Under half believed CFS was a distinct syndrome. • GPs acknowledged difficulties in management and diagnosis of CFS. • 85% indicated a need for clear diagnostic criteria.

		Status: 80% full time employment 19% part time employment Location: Australia		• 88% referred to a specialist while 77% made psychosocial referrals.
Swoboda, 2008	Contested illness	Provider Type: 445 physicians from a variety of specialties Gender: 75.3% male Location: United States	Survey	• A significant portion of physicians are diagnosing these illnesses and use different decision-making strategies than those who do not diagnose these illnesses. • Providers who diagnose these illnesses tend to manage uncertainty and think beyond current disease models.
Thomas & Smith, 2005	Chronic Fatigue Syndrome	Provider Type: 45 general practitioners Location: United Kingdom	Survey	• 56% believed CFS is a recognized condition and none reported using specific criteria for a CFS definition. • Antidepressants were the preferred treatment. • About half of GPs would welcome advice from other healthcare professionals when working with patients who they suspect may have CFS.
Wainwright et al., 2006	Medically unexplained suffering	Provider Type: 14 general practitioners Location: United Kingdom	Interviews	• The distinction between biomedical and psychological problems was based on physical pathology findings. • Observable physical pathology was on top of the moral hierarchy. • GPs were reluctant to conclude problem was psychosocial even when physical tests showed no

				evidence of pathology for fear they were missing something. • GPs thought it was difficult to shift from biomedical to psychosocial paradigm with patients for fear of the impact on the doctor-patient relationship.
Wileman et al., 2002	Medically unexplained symptoms	Provider Type: 15 general practitioners Gender: 11 male, 6 female Practice Location: inner city and suburban areas Location: England	Semi-structured interviews	• GPs thought of MUS as medicalization of distress and decreased tolerance of benign somatic symptoms. • GPs felt powerless in the face of symptoms with 'social' origin. • GPs reported social problems as cause of symptoms, and stated that current teaching about management of this group of patients did not help them. • GPs reported that the balance of power was with the patient with MUS and they were therefore seen as difficult to manage. • GPs reported needing support to manage the negative feelings and frustration that often accompanies treating these patients.

Table 3

Studies by Theme

Acceptance and Skepticism	
Acceptance	Denz-Penhey & Murdoch, 1993 Ho-Yen, 1991 Thomas & Smith, 2005
Skepticism	Asbring & Narvanen, 2003 Bowen et al., 2005 Cranford & King, 2011 Fitzgibbon et al., 1997 Horton et al., 2010 Steven, et al., 2000
Attribution of Etiology	
Psychosocial Attribution	Asbring & Narvanen, 2003 Cho et al., 2008 Dixon-Woods & Critchley, 2000 Gomez et al, 1996 Hoedeman et al., 2010 Horton-Salway, 2007 Jason et al., 2001 Prins et al., 2000 Reid et al., 2001 Richardson et al., 2001 Sharpe et al., 1994 Steven, et al., 2000 Wileman et al., 2002
Biomedical Attribution	Hellstrom et al., 1998 Jason et al., 2001 Richardson et al., 2001
Mixed Attribution	Cranford & King, 2011 Gibson & Lindberg, 2011 Philips, 2010 Richardson et al., 2001 Skovbjerg et al., 2009
Diagnostic, Treatment, and Decision Making Differences	
Diagnostic Differences	Steven, et al., 2000 Swoboda, 2008

Treatment Differences	Cho et al., 2008
	Fitzgibbon et al., 1997
	Kroese et al., 2008
	Philips, 2010
	Steven, et al.,
	Thomas & Smith, 2005
Decision-Making Differences	Dixon-Woods & Critchley, 2000
	Philips, 2010
	Swoboda, 2008
Negative Experiences with Patients	
Difficult Patients	Bieber et al., 2006
	Gomez et al, 1996
	Horton-Salway, 2007
	Prins et al., 2000
	Raine et al., 2004
	Salmon et al., 2005
	Scott et al., 1995
	Sharpe et al., 1994
	Wileman et al., 2002
Frustration	Chew-Graham et al., 2008
	Dixon-Woods & Critchley, 2000
	Hayes et al., 2010
	Hoedeman et al., 2010
	Lundh et al., 2004
	Sharpe et al., 1994
	Wileman et al., 2002
Provider-Patient Relationship	
Relationship	Chew-Graham et al., 2008
	Hartman et al., 2009
	Hellstrom et al., 1998
	Horton et al., 2010
	Salmon et al., 2005
	Wainwright et al., 2006
Lack of Confidence with Diagnosis and Treatment	
Lack of Confidence with Diagnosis	Bowen et al., 2005
	Dixon-Woods & Critchley, 2000
	Fitzgibbon et al., 1997
	Horton et al., 2010
	Prins et al., 2000

	Steven, et al., 2000 Wainwright et al., 2006
Lack of Confidence with Treatment	Bowen et al., 2005 Dixon-Woods & Critchley, 2000 Fitzgibbon et al., 1997 Gibson & Lindberg, 2011 Hayes et al., 2010 Hartz et al., 2000 Horton et al., 2010 Lundh et al., 2004 Raine et al., 2004 Reid et al., 2001 Steven, et al., 2000
Desire to Improve Knowledge	Bieber et al., 2006 Chew-Graham et al., 2008 Cranford & King, 2011 Gibson & Lindberg, 2011 Hartz et al., 2000 Richardson et al., 2001 Skovbjerg et al., 2009 Thomas & Smith, 2005 Wileman et al., 2002

CHAPTER THREE: METHOD

The purpose of this chapter is to describe the methodology for the second article of this dissertation, a qualitative phenomenological study. The methodology and research question guiding this study were created based on the findings from the systematic review, which indicated that medical providers experience frustration and a general lack of confidence when caring for patients with medically unexplained illnesses and medically unexplained symptoms (MUI/S) and that there is a need for greater understanding of the variables that contribute to providers' experiences with this group of patients.

Design

To gain an expanded, in-depth, detailed view of participants' experiences, ideas, and beliefs we chose to utilize qualitative phenomenology methodology. With attribution theory tenets and gaps in the extant literature in mind, we aimed to explore the question: "What are the personal and professional factors and experiences that contribute to medical residents' thoughts, beliefs, and clinical approaches to treating patients with MUI/S?". Phenomenological studies are designed to focus on "exploring how human beings make sense of experience and transform experience into consciousness" (Patton, 2002, p. 104). Through in-depth interviews with participants who have direct experience of the specific phenomenon being studied, investigators began to better understand how participants perceived, judged, and made sense of the phenomenon (Patton, 2002). A phenomenological research design, with its emphasis on understanding lived experience and meaning (Patton, 2002), was an appropriate method for this study since it allowed for a deeper understanding of providers' perspectives and experiences of MUI/S.

Specifically, the Transcendental Phenomenological Method (TPM) was used to guide this research project. In TPM, phenomenology refers to the "science of describing what one perceives, senses, and knows in one's immediate awareness and experience" (Moustakas, 1994, p. 28). Transcendental refers to seeing a phenomenon through personal reflection on subjective and objective components of experience (Moustakas, 1994). Additionally, since establishing the verification of study results, or "the process of checking, confirming, making sure, and being certain" (Morse et al., 2002, p. 9) is extremely important to establish and maintain rigor (Morse et al., 2002), we used a number of strategies (e.g., purposeful sampling, saturation achievement, expert audit review) to address the verification of the study results.

Participants

Consistent with the TPM process, we chose research participants who have experienced the phenomena being researched, were interested in participating in an interview, and were willing to have the interview recorded and the results from the interview published (Moustakas, 1994). In an attempt to be consistent with the terminology used in TPM, for the purpose of this study 'co-researcher' denotes study participants and 'co-investigator' denotes members of the research team.

Medical resident co-researchers were chosen to take part in this study since they are currently immersed in training programs and are able to comment on their medical school and residency education. Additionally, unlike more seasoned providers who have likely already established MUI/S treatment and diagnostic practices, residents may currently be in the process of deciding how best to treat this group of patients and have more opportunities for education concurrent with their clinical practice. Further, residents who are in their third year of internal medicine or family medicine training programs will be recruited for participation in this study

because they have amassed the largest number of inpatient and outpatient contact encounters since beginning their residency programs.

Medical resident co-researchers were considered for participation if they met the following inclusion criteria: a) are in at least the 3rd year of an internal medicine or family medicine residency program, b) have self-reported experience working with patients with MUI/S, c) are fluent in written and spoken English. Potential co-researchers were recruited through e-mail blasts to approximately 10-20 program directors and behavioral medicine directors of residency programs across the United States as well as residency program directors with whom we have existing relationships. To aid in diversity across educational programs, a maximum of four residents per program were admitted into the study. A total of ten co-researchers from five different training programs participated in the study.

Procedure

Before the data collection process began, investigators engaged in epoche, which is a process that helps investigators eliminate previous thoughts, ideas, judgments, and presuppositions regarding the research topic (Moustakas, 1994). When judgments are set aside, and the data collected can be seen with more open, fresh eyes through the epoche process. We accomplished this through keeping a journal with purposeful reflection on thoughts and feelings about the phenomena being studied.

Participant interviews. Each co-researcher took part in an interview process with the primary investigator. Interviews were conducted via Skype, which is a video software program that allowed the primary investigator and co-researchers to see each other 'face to face' during the interview via the Internet. Informed consent was obtained before the interview began and a numerical code was assigned to all co-researchers in order to protect confidentiality. Each

interview took between 30 and 60 minutes, was recorded with a digital voice recorder, and was transcribed verbatim. The interview process took place in three steps:

1. Co-researchers were asked to fill out a demographic questionnaire containing questions about their sociodemographic characteristics.

2. Co-researchers viewed a brief video via the Internet that showed a simulated provider/patient interaction in which 'patient' presents with symptoms consistent with MUI/S. Questions were then asked by the primary investigator that elicited participants' attributions regarding the simulated patient's clinical concerns and, based on their understanding of the etiology of the patient's symptoms, how they would treat the patient.

3. Following the questionnaire and the video portion of the interview, co-researchers took part in a semi-structured interview consisting of broad and clarifying questions pertaining to their experience, understanding, attitudes, and beliefs regarding MUI/S.

Data Analysis

After data were collected from co-researcher interviews, we completed an analysis of each interview followed by an analysis of the entire set of data. Our data analysis was based on Moustakas' (1994) modification of the Van Kaam (1959) Method of Analysis of Phenomenological Data. We analyzed data according to the following process (Moustakas, 1994, p. 120):

a) Interviews were transcribed verbatim and expressions from the co-researchers' experience were grouped by meaning.

b) Co-researcher's expressions were eliminated if they did not contain part of the experience that was necessary for understanding.

c) Remaining expressions were clustered into common themes while overlapping or repetitive statements were eliminated.

d) Themes were assigned a code, or a few-word phrase that captured the general meaning of each theme. We identified new codes as interviews were transcribed and analyzed, and went back to the previous interviews and recoded using the newly developed codes until all transcripts were coded with the final code list. We recognized that saturation has been achieved when there were no new themes being discussed by co-researchers that had not been mentioned in previous interviews.

e) After all of the interviews had been transcribed and coded, as described above, co-investigators developed individual textural descriptions (e.g., 'what' was experienced). Phrases such as "He believed patients often desire a label for their difficulties and found that some have stated 'I wish I knew what was going on.'" were included in the textural descriptions.

f) Individual structural descriptions (e.g., 'how' the experience happened) for each co-researcher was developed based on the themes found in each transcript. "This participant's lack of formal education, and the conflicts between his experiences in medical school and his experiences in residency have left him feeling frustrated when working with pts with MUI/S." is an example of the information included in the structural descriptions.

g) At this point, co-investigators synthesized, or merged, the individual textural and individual structural descriptions into a textural-structural description that created a "unified statement of the essences of the experience of the phenomenon as a whole" (Hesserl, as cited in Moustakas, 1994, p. 100) for each co-researcher. Then, the individual textural-structural descriptions for each co-researcher were synthesized to create a composite description of the meanings and essences of the experience from all of the co-researchers that represents the group

as a whole (Moustakas, 1994). In phenomenological research, this step is commonly known as the 'phenomenological summary'.

Study Verification Strategies

Strategies for establishing the verification of study results, or "the process of checking, confirming, making sure, and being certain" (Morse et al., 2002, p. 9) are extremely important to employ throughout a qualitative research project to establish and maintain rigor (Morse et al., 2002). Thus, in addition to the TPM procedures, a number of strategies were used to address the verification of the study results. The following is a list of these strategies, some of which have been mentioned briefly throughout this section.

- Purposive sampling: This is a strategy used by qualitative investigators to select information-rich co-researchers to increase the depth of the study (Patton, 2002). Co-researchers for the proposed study will be recruited from Family Medicine and Internal Medicine residency programs in the United States. Co-researchers were chosen only if they have had experience with the phenomenon being studied, meet the inclusion criteria, and consented to participate in the study.

- Audit trail: An audit trail includes a research log and reflections that are kept in a reflexive journal (Ahern, 1999), investigator interpretations, and a data analysis log (Wolf, 2003). We utilized reflexivity exercises in the epoche process and kept an ongoing log of our interpretations of the data and data analysis process.

- Saturation achievement: Saturation is achieved when interviews with new co-researchers are no longer resulting in new information (Patton, 2002). We reviewed each interview transcript multiple times, as soon as data collection began, so that we could discover when data saturation had been achieved.

- Triangulation: This technique involves using several different kinds of methods or data to increase the credibility of the study results (Patton, 2002). In this study, the video portion of the interview and the semi-structured, open-ended portion of the interview provided co-investigators with the opportunity to determine whether what co-researchers said they would do in response to the video was consistent with their answers to the open-ended questions. Additionally, two co-investigators transcribed and coded data, which further added to the triangulation of results.

- Epoche: This technique, which is discussed in detail in the 'Methods of Collecting Data' section, involves the investigators paying attention to the personal values, biases, and beliefs they hold that may impact the study results (Moustakas, 1994). In this study, each co-investigator participated in the epoche process before the study began and throughout the data collection and analysis process.

- Member check: This technique is used to verify qualitative study results (Patton, 2002). We emailed co-researchers and asked them to verify study findings.

Summary

The goal of this project was to gain a deeper understanding of the variables that influenced the way medical residents experience patients who present with MUI/S. The lack of available literature on this topic, in addition to the high prevalence of patients with MUI/S seen in primary care settings served as the catalysts for this project. Through this study, we aimed to provide greater insight into how medical residents view caring for this group of patients, and how their experiences influenced their clinical approach.

REFERENCES

Ahern, K. J. (1999). Pearls, pith, and provocation: Ten tips for reflexive bracketing. *Qualitative Health Research, 9*(3), 407-411.

Bieber, C., Muller, K. G., Blumenstiel, K., Schneider, A., Richter, A., Wilke, S., … Eich, W. (2006). Long-term effects of a shared decision-making intervention on physician-patient interaction and outcome in fibromyalgia. A qualitative and quantitative 1 year follow-up of a randomized controlled trial. *Patient Education and Counseling*, *63*, 357-366. doi:10.1016/j.pec.2006.05.003

Dwamena, F. C. (2007). *Treating medically unexplained symptoms: An evidence-based method* [PDF document]. Retrieved from Society of General Internal Medicine Website: http://www.sgim.org/

Fortin, A. H. (2004). *Learning and teaching an evidence-based method for patient-centered interviewing* [PDF document]. Retrieved from Society of Teachers of Family Medicine Website: http://www.stfm.org

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods, 18*(1), 59-82.

Johnson, S. K. (2010). *Medically unexplained illness: Gender and biopsychosocial implications*. Washington, DC: American Psychological Association. doi:10.1037/11623-000

Morse, J. M., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods 1*(2). Retrieved from http://www.ualberta.ca/~iiqm/backissues/1_2Final/pdf/morseetal.pdf

Moustakas, C. (1994). *Phenomenological research methods*. Thousand

Oaks, CA: Sage.

Patton, M. Q. (2002). *Qualitative research & evaluation methods* (2nd ed.). Thousand

Oaks, CA: Sage Publications.

van Kaam, A. (1959). Phenomenal analysis: Exemplified by a study of the experience of "really

feeling understood." *Journal of Individual Psychology, 15*(1), 66-72.

Wolf, Z. R. (2003). Exploring the audit trail for qualitative investigations. *Nurse Educator,*

28(4), 175-178.

CHAPTER FOUR: MEDICAL RESIDENTS' EXPERIENCES WITH MEDICALLY

UNEXPLAINED ILLNESS AND MEDICALLY UNEXPLAINED SYMPTOMS

Medically unexplained illnesses (MUI) are characterized by a cluster of unexplained

medical symptoms that fit with the diagnostic criteria for a recognized unexplained illness

(Dumit, 2005). Illnesses such as gulf war syndrome (GWS), chronic fatigue syndrome (CFS),

fibromyalgia syndrome (FM), and multiple chemical sensitivity (MCS) are examples of MUI and

are often chronic and lack a definitive biological basis, diagnosis, treatment, and prognosis

(Dumit, 2005). Patients with MUI and with medically unexplained symptoms (MUS) often

report having difficult experiences with the medical community (Bieber et al., 2006; Dumit,

2005; Reid, Whooley, Crayford, & Hotopf, 2001; Swoboda, 2008). The main distinction between

MUI and MUS is that while MUS are characterized by one or more physical symptoms, unlike

MUI, they do not fit with diagnostic criteria for a recognized unexplained illness, and cannot be

explained by corresponding physical pathology (Swanson, Hamilton, & Feldman, 2010).

Researchers have estimated that approximately 25-50 percent of patients seen in primary

care present with MUS, which makes MUS the most common set of complaints seen by primary

care providers (Edwards, Stern, Clarke, Ivbijaro, & Kasney, 2010). Further, people with either

MUS or MUI tend to be higher utilizers of healthcare services and have significantly greater

healthcare costs than other patients (Burton, McGorm, Richardson, Weller, & Sharpe, 2012;

Reid et al., 2001), which can add stress and strain for the patient, family, provider, and other

members of the patient's healthcare team (Gibson, 2006).

Through a systematic review of the literature this team of researchers found that medical

providers varied greatly in their thoughts about MUI/S, including the diagnoses given (e.g.,

Steven et al., 2000), treatment protocols applied (e.g., Cho, Menezes, Bhugra, & Wessely, 2008),

decision-making strategies used (Phillips, 2010; Swoboda, 2008), and attributed causes for their development. Psychosocial attributions (e.g., a pessimistic view of life; Asbring & Narvanen, 2003), biomedical attributions (e.g., immune system dysfunction; Denz-Penhey & Murdoch, 1993), or a combination of psychosocial and biomedical factors (e.g., Gibson & Lindberg, 2011; Phillips, 2010) were found to be primary causes, but there was no agreement among the researchers on which attributions carried more empirical merit.

Understandably, with such a lack of agreement among providers, working with patients with MUI/S led to high levels of provider frustration (e.g., Hartman, Hassink-Franke, Lucassen, van Spaendonck, & van Weel, 2009; Hayes et al., 2010; Lundh, Segesten, & Bjorkelund, 2004; Swoboda, 2008), lower confidence in treatment and diagnosis (e.g., Bowen, Pheby, Charlett, & McNulty, 2005; Dixon-Woods & Critchley, 2000; Fitzgibbon, Murphy, O'Shea, & Kelleher, 1997), and a dearth of protocols for effective treatment (e.g., Bieber et al., 2006; Reid et al., 2001; Swoboda, 2008). It appears that providers are unsure what the entry point is to helping patients manage their illnesses and symptoms (i.e., psychosocial, biomedical, or both), and much of this confusion may stem from lack of uniformity in how they were prepared to care for this population.

Education and Training

Although patients with MUI/S tend to be higher utilizers of healthcare services and have significantly greater healthcare costs than other patients (Burton et al., 2001), there is insufficient research on how the medical education system may better prepare providers to care for patients with MUI/S. Findings from the authors' (2013) systematic review revealed a relative paucity of research on the type or quality of preparation offered to providers for treating patients with MUI/S. To date, Bieber et al. (2006) were the only researchers to discuss coursework and

educational opportunities in this area. Using both qualitative and quantitative methods, Bieber et al. (2006) found that patients reported greater improvements in 'coping' measures when they received care from practicing physicians who underwent a shared decision-making training. To better understand findings from previous studies and how they related to the current study, we chose to employ a unifying theory, attribution theory, as a lens through which to view results.

Theoretical Underpinning

Attribution theory has been incorporated into our study design as a lens through which to view research processes and outcomes. Attributions are the results of cognitive processes that help people apply cause and effect to interactions with their environment (Martinko, Harvey, & Douglas, 2007). Because of people's innate drive to search for causes of phenomena (Borkowski & Allen, 2003; Weiner, 2008), control their environments (Borkowski & Allen, 2003), and explain or understand the behaviors of self and others (Cranford & King, 2011; Martinko et al., 2007), attributions are assigned to events and occurrences.

The basic tenets of attribution theory can be applied to the healthcare system and more specifically to the behavior of providers who treat patients who have MUI/S. In a healthcare setting, medical providers treat patients based on the attribution (e.g., biomedical, psychological, social) of patients' symptoms. Whether done consciously or unconsciously, providers attempt to explain why people behave in a certain manner and attribute patients' symptoms to a certain cause (e.g., organic illness, psychological difficulty, trauma-related issue). Thus, patient treatment stems from what the provider believes is responsible for causing the symptoms or illness.

Considering the tenets of attribution theory, as well as the aforementioned gaps in the literature, this phenomenological study was conducted to discover residents' experiences caring

for patients with MUI/S and the personal and professional factors that contribute to their clinical approaches and preparedness for caring for this population.

Method

To gain an expanded, in-depth, detailed view of participants' experiences, ideas, and beliefs, we chose to utilize qualitative phenomenology methodology. We aimed to explore the following research question: "What are the personal and professional factors and experiences that contribute to medical residents' thoughts, beliefs, and clinical approaches when treating patients with MUI/S?"

Phenomenological studies are designed to focus on "exploring how human beings make sense of experience and transform experience into consciousness" (Patton, 2002, p. 104). Through in-depth interviews with participants who have direct experience with the specific phenomenon being studied, investigators can begin to better understand how participants perceive, judge, and make sense of it (Patton, 2002). A phenomenological research design, with its emphasis on understanding lived experience and meaning (Patton, 2002), was selected for this study because it allowed for a deeper understanding of providers' perspectives and experiences of MUI/S.

Specifically, the Transcendental Phenomenological Method (TPM; Moustakas, 1994) was used to guide this research project. In TPM, phenomenology refers to the "science of describing what one perceives, senses, and knows in one's immediate awareness and experience" (Moustakas, 1994, p. 26). Transcendental refers to seeing a phenomenon through personal reflection on subjective and objective components of experience (Moustakas, 1994). When relying on the subjective descriptions of an experience and the co-investigators' management of data, controlling one's own biases calls for methods that can assist in verifying the findings to

establish and maintain rigor (Morse et al., 2002). Thus, verification methods (purposive sampling, audit trail, saturation achievement, expert audit review, triangulation, and epoche) were employed to verify the study's results and remain faithful to the participants' experiences during the analysis process.

Co-Researchers

Consistent with the TPM process, we chose research participants who have experienced the phenomenon being researched, were interested in participating in an interview, and were willing to have the interview recorded and results published (Moustakas, 1994). In an attempt to be consistent with the terminology used in TPM, for the purpose of this study 'co-researcher' denotes study participants and 'co-investigator' denotes members of the research team.

Family medicine and internal medicine residents in their third year or beyond were chosen as the study's co-researchers since they are currently immersed in training programs and are able to comment on their medical school and residency education with recency. Additionally, unlike more seasoned providers who have likely already established MUI/S treatment and diagnostic practices, residents may currently be in the process of deciding how best to treat this group of patients, have a variety of faculty educators with varying perspectives, and have more opportunities for education concurrent with their clinical practice. Further, residents who are in their third year of internal medicine or family medicine training programs have amassed the largest number of inpatient and outpatient contact encounters since beginning their residency programs and would be more likely than residents in their first or second year of training to have experiences treating patients with MUI/S.

Co-researchers were considered for participation if they met the following inclusion criteria: a) were in at least the 3rd year of an internal medicine or family medicine residency

program, b) had self-reported experience working with patients with MUI/S, and c) were fluent in written and spoken English. Co-researchers were recruited through e-mail blasts sent to directors of family and internal medicine residency programs across the United States. To aid in diversity across educational programs, a maximum of four residents per program were admitted into the study. Ten co-researchers from five different training programs participated in this study, eight males and two females.

Procedure

Before the data collection process began, investigators engaged in epoche, which is a process that helps investigators eliminate previous thoughts, ideas, judgments, and presuppositions regarding the research topic (e.g., journaling about biases; Moustakas, 1994). When judgments are set aside, the data collected can be seen with more open and fresh eyes. Investigators accomplished this through keeping a journal with purposeful reflection on thoughts and feelings about the phenomena being studied. This journal was reviewed at each stage of the analysis process.

Each co-researcher took part in an interview process with the primary investigator, after the investigators obtained approval from the Internal Review Board and informed consent from each co-researcher. Interviews were conducted via a video software program that allowed the primary investigator and co-researchers to see each other 'face to face' during the interviews. Informed consent was obtained before the interview began, and a numerical code was assigned to all co-researchers to protect confidentiality. Interviews took between 30 and 60 minutes, were recorded with a digital voice recorder, and were transcribed verbatim. The interview process took place in three steps:

1. Co-researchers were asked to fill out a demographic questionnaire containing questions about their sociodemographic characteristics.

2. Co-researchers viewed a brief video via the Internet that showed a simulated provider/patient interaction in which 'patient' presented with symptoms consistent with MUI/S. Questions were then asked by the primary investigator that elicited co-researchers' attributions regarding the simulated patient's clinical concerns and, based on their understanding of the etiology of the patient's symptoms, how they would treat the patient. A full list of interview questions can be found in Figure 1.

3. Following the questionnaire and the video portion of the interview, co-researchers took part in a semi-structured interview consisting of broad and clarifying questions pertaining to their experience, understanding, attitudes, and beliefs regarding MUI/S.

Data Analysis

After data were collected from co-researcher interviews, we completed an analysis of each interview followed by an analysis of the entire set of data. Our data analysis was based on Moustakas' (1994) modification of the Van Kaam (1959) method of analysis of phenomenological data. We analyzed data according to the following process (Moustakas, 1994, p. 120):

1. Interviews were transcribed verbatim and expressions from co-researchers' recorded statements were grouped by meaning.

2. Co-researchers' expressions were eliminated if they did not contain mention of an experience related to the purpose of the study (e.g., reports of education on topics other than MUI/S).

3. Remaining expressions were clustered into common themes and overlapping or repetitive statements were eliminated.

4. Themes were assigned a code or a few-word phrase that captured their general meaning. We coded each interview in the order in which it was transcribed. As new codes were identified, investigators went back through the previous interviews and recoded each one using the newly developed codes until all transcripts were coded with the final code list. We repeated this process until saturation had been achieved and no new themes emerged.

5. After all of the interviews had been coded as described above, co-investigators developed individual textural descriptions (e.g., 'what' was experienced). Phrases such as, "He believed patients often desire a label for their difficulties and found that some have stated 'I wish I knew what was going on'" were included in the textural descriptions.

6. Individual structural descriptions (e.g., 'how' the experience happened) were developed based on the themes found in each transcript. "This co-researchers' lack of formal education and the conflicts between his experiences in medical school and his experiences in residency have left him feeling frustrated when working with patients with MUI/S" is an example of the information included in the structural descriptions.

7. After each interview was coded, co-investigators synthesized, or merged, each individual's textural and structural descriptions into a textural-structural description that created a "unified statement of the essences of the experience of the phenomenon as a whole" (Hesserl, as cited in Moustakas, 1994, p. 100) for each co-researcher. Then, the individual textural-structural descriptions for all co-researchers were synthesized to

create a single composite description of the meanings and essences of their experiences that represented the group as a whole (Moustakas, 1994). In phenomenological research, this step is commonly known as the 'phenomenological summary.' The following results reflect a composite description of the meanings and essences of co-researchers' thoughts, beliefs, and experiences regarding MUI/S.

Results

Through the data analysis process outlined above, six core themes emerged: (a) medical education, (b) provider and patient frustration, (c) integrated care, (d) rewards and benefits, (e) provider/patient relationship, and (f) co-researcher attributions of MUI/S. Additionally, within each main theme, a number of sub-themes emerged. Themes and sub-themes, as well as the frequency of co-researcher responses for each thematic category, are outlined in Table 2. Utilizing these core themes and sub-themes as our guide, we developed a composite description of co-researchers' experiences.

Theme 1: Medical Education

Sub-theme 1: Lack of education. Ninety percent of co-researchers' first reactions to the topic of MUI/S and to the video of the mock patient/provider interaction were statements about the frequency of encounters with MUI/S patients. They felt as though they had 'seen this patient before'. However, the majority of co-researchers reported a lack of formal education about MUI/S during their medical school training. Half of the co-researchers echoed the sentiment "I think that our medical education is not doing a very good job of teaching us to treat patients with medically unexplained illness." They believed the lack of medical school training about MUI/S was due to the amount of teaching necessary about "diagnosable illnesses." Co-researchers

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believed they would feel more confident in treating patients with MUI/S if they had more training on how to differentiate between biomedical and psychosocial diagnoses.

Sub-theme 2: Helpful educational opportunities. Eighty percent of co-researchers reported learning a small amount of information about MUI/S while in medical school. One co-researcher reported having a few hours of *class lecture* spent on MUI/S, which he deemed "the side of medicine that we don't learn in textbooks." This class touched on "what do you tell a patient when you don't know what the diagnosis is?" Also, co-researchers mentioned that they had "a lot of simulated patients and patient encounters that kind of presented this way where there was a lot of multiple somatic complaints and you would try to get down to the root of what was really going on." These courses and didactics were reported as helpful training opportunities. Further, another co-researcher reported they "were trained heavily in behavioral medicine so coming out of medical school and seeing patients like this I had a really good understanding they aren't crazy."

Residency training was mentioned as co-researchers' main source of education for how to work with this group of patients. Co-researchers deemed residency the setting that helped them to feel comfortable treating patients with MUI/S and that assisted them in feeling more confident. Contact with patients in "difficult situations" and with "social situations and behavioral issues" helped residents to see a possible connection between medical symptoms and psychosocial stressors.

Patient contact during residency was discussed as the most helpful tool for increasing confidence in managing patients with MUI/S. Residents reported, "I feel like the more and more you see them, the better you feel about taking care of their issues." Residents also felt that "just being exposed to the patients" was helpful as was "experience" and "trial and error."

Mentorship was also highlighted as an experience that assisted co-researchers in becoming confident in caring for patients with MUI/S. Talking with mentors who say "sometimes we don't find a diagnosis for everything" was reportedly helpful for sixty percent co-researchers. Since they learned in medical school that "there's definitely a diagnosis for everything," it helped them to hear mentors at their residency site say "we don't always find a diagnosis." Thirty percent reported that they felt fortunate to have had a mentor who helped them accept the idea that they would not always have an answer. They reported it was helpful when, "instead of saying 'have you thought about every possible thing on the differential'… having attendings that will say 'you know sometimes we just don't know.'"

With frequency, co-researchers echoed the sentiment that learning "it's not wrong to say 'I don't know'" has been a key component in increasing their confidence in working with patients with MUI/S. Eighty percent reported an understanding that some patients' symptoms may never be cured and one resident said, "We don't have answers for everything even though we like to say we do or think we can." Another co-researcher expressed the thought,

> As long as we are paying the patient attention, we are not going to go wrong. If you are listening to them and try to answer their questions, sometimes they don't always hear it, but as long as you are trying to do what is best for them you are going to be okay… that's my philosophy.

Frequent visits were also discussed as a helpful tool to utilize with patients who present with MUI/S. One resident reported that visits as often as "every two weeks" with patients can help with treatment of their symptoms. For example, one co-researcher discussed a case in which frequent visits have been helpful. He mentioned:

I have a particular patient who has multiple ED (emergency department) visits. She is an extreme overuser. No-shows and shows for lots of clinic visits. I try to see her regularly because it seems to be one of the few things that will actually keep her out of the ED.

From what he has experienced and read, he believes that there is "not much that can be done except consistent follow up."

Residents' personal experiences, for twenty percent of the co-researchers, such as those with their own chronic pain and stress headaches, have aided co-researchers in developing their own ideas about what causes MUI/S and has helped them to be "far more empathic" with patients. Also, a resident mentioned their own internal processes of "learning how to be more comfortable in my own skin" and the ability to "recognize my own bias toward the patients more readily." Recognizing the importance of personal processes and patience with patients and self, another resident stated, "I think I can do better by them if I am more at peace with myself when they came in." This was echoed by a co-researcher who mentioned,

Being patient with people whenever you see them, not be to frustrated with them when you see them on your schedule…that's probably the hardest thing is not being frustrated with them, and that's something that I deal with myself; as I am becoming more experienced in practicing medicine, those things don't bother me as bad as they did two or three years ago.

Sub-theme 3: Conflicting information between medical school and residency. Forty percent of co-researchers reported learning conflicting information between medical school and residency. For example, "in med school it's all about knowing the answers because you're expected to know so when you don't know it's like 'well, I must be doing something wrong.'" However, during residency they found that when patients come to the clinic with unexplained

symptoms, it throws medical school training on diagnostic and treatment practices "out the window."

Residency also allowed co-researchers to learn about the difference between how information is presented in medical school and how patients actually present. One co-researcher noted "…at med school somebody had this disease and that's how they present, and in residency, in real life, that is never the case. Very rarely [do] people ever present textbook…" Additionally, while in medical school many co-researchers reported that they were "always taught in medical school that there is one unifying diagnosis for all their [patient's] symptoms," while during residency they did not find this to be true in practice.

Sub-theme 4: Confidence and preparedness. All in all, eighty percent of co-researchers reported that they felt prepared to work with patients with MUI/S. They ranged from feeling "very comfortable" to "adequately prepared." Co-researchers felt "pretty confident that I can help people with it [MUI/S]" and felt comfortable based on previous success with patients. One co-researcher reportedly felt fairly prepared even though they "can't guarantee that it would always go that well" and "can always get better at it."

One co-researcher reported that they believed they would be more prepared to work with a patient with MUI/S if they were involved from the beginning of the diagnostic process so they could build a strong relationship with the patient from the outset, instead of coming into the process in the middle when the patient may already have existing expectations and frustrations with medical care.

Theme 2: Provider and Patient Frustration

Sub-theme 1: Resident frustrations. In each of the ten interviews, co-researchers discussed their frustration in working with patients with MUI/S. They shared the sentiment,

"From a physician standpoint it [MUI/S] can be very frustrating." The differences in treatment and outcome expectations between provider and patient were reported as a main contributing factor in provider frustration. Co-researchers discussed wanting to "find something to treat" and becoming frustrated when they could not. One resident reported that they felt that MUI/S "throws a huge monkey wrench in that [the diagnosis and treatment process] and [when] it doesn't work out so well, it becomes frustrating." Another found MUI/S to be an "annoying" and a "really challenging part of medicine."

One resident reported that they found it "hard not to get personally frustrated as well… by the situations, not by the patients." When working with this group of patients another found it "humbling that we don't always find an answer and I think that… I think it's hard; it's time-consuming." Thirty percent of co-researchers recognized their limitations but found that some frustrations stemmed from the idea that "it's hard for providers to admit sometimes that we are limited." Thus, one resident reported feeling that "the negative outweighs the positives" in working with this group of patients.

Due to previous experiences with patients with MUI/S, eighty percent of co-researchers reported a negative and even a "visceral gut reaction" to watching the mock provider/patient encounter video. This was reportedly partially due to the time-consuming nature of the provider/patient encounters with MUI/S patients and the idea that "sometimes you feel like you aren't making much headway." They have also found MUI/S patients can be "more demanding," "needy," and "high utilizers" of the medical system since they are often "resistant" "about opening up and accepting that maybe these are somatic complaints." One co-researcher found themselves "heartbroken" after encounters with this group of patients and felt the need to "talk to someone about it because I felt like I had failed with her."

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Co-researchers discussed some specific frustrations surrounding the diagnostic and treatment processes. One reported having a difficult time understanding "when do we stop digging" after multiple tests. They were taught to "first do no harm" and twenty percent believed it was important to stop ordering imaging and tests and to stop prescribing medications that could have adverse side effects, in an attempt to prevent creating more difficulties for the patient. One provider noted "how much harm we can do and how much worse we can make these situations a lot of times" in a "well-intentioned" effort to help patients.

Along the same line of thought, twenty percent of co-researchers expressed their belief that labeling a patient with a specific diagnosis just to put a name to their symptoms can be detrimental. For example, one co-researcher stated,

> I feel like a lot of our diagnoses out there that we have developed recently have come from medically unexplained illness. Things like irritable bowel -- I mean there are symptoms. It is a real thing like fibromyalgia; I am trying to think of others. We almost just hang these on people when they have pain we can't explain or belly pain we can't explain.

These co-researchers felt that some of the labeling comes from providers' perceptions that patients often desire a label for their difficulties and some have encountered patients that have made statements such as, "You could at least say its cancer or something so at least I could have an answer." They believe that there have been illnesses like "irritable bowel syndrome, fibromyalgia, and chronic pain that become these 'wastebasket diagnoses' when doctors don't know what's going on but they try to find a category to throw it in so they can label the patient with something."

Sub-theme 2: Patient frustrations. Seventy percent of co-researchers also recognized the impact that seeking treatment for MUI/S can have on patients. They believed that having an MUI/S had to be "obviously scary" and "frustrating" for patients. These o-researchers believed that seeking treatment could be "a very expensive process for the patient because they're seeing different specialists that try to find exactly what's happening." They recognize that patients become frustrated and angry and often come "perhaps with an appropriate chip on their shoulder toward the healthcare system that has failed them so far."

These residents also indicated that the diagnostic and treatment process could be frustrating for patients if they feel all of their issues are blamed on psychosocial reasons when they think there is biomedical etiology. They found that patients "come in either frustrated, angry, or just worn out by the process" when they believe "there's something awful wrong with me," yet providers have not given them an answer.

Theme 3: Integrated Care

Sixty percent of co-researchers denoted the benefits of having a behavioral healthcare provider to assist them with the diagnosis and treatment process for patients who present with MUI/S. For example, one co-researcher communicated his belief that "having a psychologist or psychiatrist or somebody to whom I could say 'How would you… kind of, deal with this with the patient?' to kind of help me out along the way" was helpful in treating patients with MUI/S.

They discussed the positive impact of collaborating with behavioral health providers and thought that a "multidisciplinary approach" would be best in treating the patient seen in the mock video. Due to their own lack of time for patient encounters, these co-researchers discussed the benefit of having someone available to "sit down and really talk for 30 or 60 minutes" with the patient. Co-researchers even reported that a large part of their confidence in working with this

group of patients "stems from the fact that I have some resources available to me in my clinic," like a social worker or a marriage and family therapist to help patients and patients' spouses work through relational difficulties. When they know they can "partner up and help these patients," it provided them with increased confidence. In fact, co-researchers reported that since "having available a behavioral health component is enormously helpful," they are nervous about taking jobs in the future where they may not have access to behavioral health professionals.

Theme 4: Rewards and Benefits

Although there were many frustrations mentioned during the interviews, seventy percent of co-researchers did report a number of rewards and benefits they have experienced when working with this group of patients. One co-researcher believed patients with MUI/S "can be kind of fun at times, like a challenge, like, 'Okay can I help them somehow?'" Others have found that making "a little bit of progress" over time with these patients can be rewarding. "The longer I can get them to stay out of the ED the better," and being able to help patients reduce their pain and anxiety medication can be "a real fight" but rewarding at the same time. Further, developing a trusting relationship with patients and seeing symptoms become "less of a bother" to the patient over time has led co-researchers to feel they were having a positive impact on their patients' lives.

The most commonly reported benefit came in the form of discussions surrounding symptom relief. These co-researchers discussed the importance of helping patients "feel better" so they can participate in their "day to day activities" even if the provider cannot find the underlying reason for their symptoms. Management versus a cure was discussed by a majority of the co-researchers. For example, one co-researcher reported trying to "patch a few holes here and

there" while they try to figure out the underlying cause of the patient's symptoms. They reportedly aimed to try "every resource you have out there to find out if something works."

Theme 5: Provider/Patient Relationship

Ninety percent of co-researchers reported greatly valuing the provider/patient relationship, and believed a strong, trusting relationship is responsible for success with MUI/S patients. They have seen patients respond better when providers are "more present with them… not as rushed to get out of there." These co-researchers thought that building a strong relationship with patients was responsible for helping patients trust their provider, feel listened-to, and helped patients to share their true feelings about their symptoms and the "other things that are going on" in patients' lives. For example, one resident stated:

> Voltaire, the famous enlightenment author, always said, 'Doctors are men who prescribe medicines of which they know little, to cure diseases of which they know less, in human beings of whom they know nothing.'

Due to co-researchers' desires to help patients "feel better," they reportedly attempt to validate and reassure patients as much as possible, even though some co-researchers reported being unaware of whether or not reassurance helps patients when they are not given a biomedical explanation for their symptoms. Co-researchers reported that experience with patients helped them to see that listening and validating patients' fears is an instrumental part of healthcare. Reassurance was reported often as more important than running tests and making referrals to specialists. For example, one co-researcher reported telling their patients "your symptoms aren't necessarily raising any red flags that you have cancer or that you have a brain tumor" and "I'm going to do an evaluation to make sure that the things I know how to treat or the things I know are going to kill you-- I look for them and make sure that they're not there," in an attempt to

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reassure them that there does not seem to be anything life threatening. An "understanding ear" was also mentioned as a key factor in successfully treating patients with MUI/S, as was playing "the role of the cheerleader."

Additionally, one co-researcher reported that "it is important to acknowledge that their pain is real, so even if I don't necessarily believe that this person may have real disease... it is really important to acknowledge and validate people…the way they feel." From the very beginning of the relationship between patient and provider, a co-researcher noted that it is important to "start off by making sure that she knows I listen and I believe her… and I do believe her." Although they have found it difficult at times, these residents believed that collaborating with patients to help make sense of their symptoms and discussing treatment options has lead to increased success in managing patients with MUI/S.

Theme 6: Co-researcher Attributions of MUI/S

Sub-theme 1: Psychosocial etiology. Ninety percent of co-researchers reported that one of the first steps in working with a patient who presented with MUI/S would be to rule out possible biomedical etiology for the patient's symptoms by reviewing the patient's chart and conducting a medical evaluation. They believed a medical work-up must be done and providers should "not just quickly say, 'Oh it's just from stress and depression or something else that's going on.'" They begin with the idea that "there is something out there you haven't found." Co-researchers believed they should complete an "appropriate medical evaluation" because they "owe it" to the patient to give them the "benefit of the doubt" before assuming symptoms stem from psychosocial etiology.

Psychosocial etiology was discussed by ninety percent of co-researchers as a possible reason for MUI/S. The residents saw MUI/S symptoms as "related to stress," "somatoform

disorder," "some type of mental illness," "depression," "anxiety," "psychiatric illness," and also related to a "behind-the-scenes social interaction" like "abuse." They tended to believe symptoms were psychosocial in nature when they "hear a lot of the nonspecific complaints that may or may not be linked together in some way" or when test results do not provide a biomedical explanation for the patient's symptoms.

One co-researcher reported that they recognized patients come from "different backgrounds and respond to different things in different ways and a lot of times they try to reach out for help by presenting with somatic complaints and that they may not know that they are doing that." They also thought patients' "preoccupation with something being wrong in itself could cause the pain or discomfort…" or because "some people process pain differently." Thus, these residents discussed psychosocial treatment for symptoms, such as cognitive behavioral therapy, referrals to psychiatry, and "some sort of talk therapy." One resident thought it would be most helpful in treating patients with MUI/S to "provide social support, maybe doing less medically and more socially and more psychosocially."

Sub-theme 2: Combined etiology. Although biomedical etiology was not discussed as the sole reason, eighty percent of co-researchers did discuss a possible combination of biomedical and psychosocial reasons for MUI/S. These residents' experiences during their contact with this group of patients led them to see the connection between physical symptoms and "other factors" present in patients' lives. They thought that discovering whether symptoms were psychosocial or biomedical in nature was "a haphazard chicken or egg situation where you don't know whether it is the symptoms that are causing you to be depressed and frustrated or whether this is a manifestation of something else." They found that "it's usually a constellation" of reasons for MUI/S and found that they "can't always differentiate in my mind what might be

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more medical or what might be more primary psychiatric versus just symptoms leading to, like I said, the depression and that sort of thing."

Due to the perception that MUI/S may result from a combination of etiologies, seventy percent of co-researchers discussed the use of biomedical and psychosocial treatment and management strategies, in conjunction, as helpful to this group of patients. Examples include a combination of "healthy eating," "exercise," "eliminate cigarettes," "eliminate drinking," "pharmacotherapy," "non-pharmacotherapy," "alternative medicine," "acupuncture," "massage therapy," and "biofeedback." They found that using a "combined approach," which included treating patient symptoms with biomedical therapies, while also employing psychosocial treatments to attend to patient difficulties, has been helpful. One resident stated, "What I think benefits people in those situations is a willingness to try everything." Thus, they would recommend lifestyle changes.

Sub-Theme 3: Gaps in biomedical knowledge. Along with biomedical and psychosocial reasons for MUI/S, thirty percent of co-researchers believed that there may be real gaps in biomedical knowledge, and, thus, the biomedical components of patient symptoms may be present, but not yet possible to find using medical tests. These residents believed,

> There is a subset out there that we can't really explain at this point. There are things going on that we don't fully understand. The biology of certain organ systems, it's based on theory. Especially when you get down to the biochemical level, there are things that we don't fully understand.

One co-researcher added, "Look back on what medicine didn't know a hundred years ago and what we know now. I think it's arrogant to think that we're at some place in medicine where we

know everything." Further, these co-researchers believed that there might be "something there we haven't found a test for."

Essence of Experience

In sum, according to the results of this study, there were many factors that are associated with medical residents' thoughts, beliefs, and experiences regarding MUI/S. Overall, a paucity of formal education on MUI/S was reported. However, co-researchers reported that positive experiences with mentors, education during medical school, and patient contact during residency programs lead to increased confidence in treating patients who present with MUI/S. Frustration surrounding MUI/S was a prominent theme, but was often relieved when co-researchers felt they could utilize resources, such as collaboration with behavioral health professionals or complementary and alternative medicine treatment options, to assist them in their work with this group of patients. Further, building trusting relationships with patients was communicated by co-researchers as a necessary step in effectively treating MUI/S patients. Finally, a combination of psychosocial and biomedical etiologies were discussed as the reason for MUI/S, and residents reported employing a 'combined approach' that included both psychosocial and biomedical treatments.

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Discussion

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In this study, we investigated the personal and professional factors and experiences that contributed to medical residents' thoughts, beliefs, and clinical approaches to treating patients with MUI/S. Inconsistent with previous researchers' reports that providers expressed low confidence in treatment and diagnosis (e.g., Bowen et al., 2005; Dixon-Woods & Critchley, 2000; Fitzgibbon et al., 1997), we found that co-researchers reported feeling prepared to diagnose, treat, and manage patients with MUI/S. Also inconsistent with previous reports that

found providers lacked protocols for effective treatment strategies (e.g., Bieber et al., 2006; Reid et al., 2001; Swoboda, 2008), many co-researchers in our study reported a number of biomedical and psychosocial strategies that they have found helpful when working with MUI/S patients. However, our results were consistent with previous reports that linked MUI/S with provider frustration (e.g., Hartman et al., 2009; Hayes et al., 2010; Lundh et al., 2004; Swoboda, 2008). Further, in line with reports from previous groups of researchers (e.g., Gibson & Lindberg, 2011; Phillips, 2010; Richardson et al., 2001), we found that provider attributions of MUI/S varied. While psychosocial attributions were reported most frequently, biomedical attributions and a combination of psychosocial and biomedical factors were also discussed.

In addition to the outcomes described above, this study also resulted in findings not previously documented in the literature on providers' view of MUI/S. First, regardless of what they believed to be the root cause for MUI/S, thirty percent of co-researchers believed medical knowledge is not yet advanced enough to fully understand the physiological processes at work in patients' bodies. Co-researchers reported that, consequentially, unnecessary tests and medications are used. Second, forty percent of co-researchers discussed the differences in training between medical school and residency programs and the often-confusing nature of conflicting information. For example, residents found their first-hand experience with MUI/S patients during residency was vastly different than the case examples they were presented with in medical school in which they were able to provide patients with a way to 'fix' their medical problems.

Third, seventy percent of co-researchers mentioned numerous rewards and benefits associated with caring for patients with MUI/S, such as keeping patients out of the emergency room and helping relieve patients' symptoms. This was the first known study that captured how

treating patients with MUS/I can be rewarding rather than only frustrating, opening up conversations in training that are empowering of patients and providers as a team and facilitating a strengths-based patient-provider relationship. With a focus on creating positive, sustained partnerships between providers and patients, these results are consistent with the goals of the patient-centered medical home model of primary care (Stange et al., 2010), which aims to create care environments that provide quality, coordinated, patient-centered, comprehensive care (Robert Graham Center, 2007).

Limitations

Differences in findings reported in the literature and the unique contributions from the current study may be the result of a constellation of factors. First, the sample of co-researchers in the current study was heterogeneous in nature, with ninety percent white and eighty percent male, which could have skewed our findings. Second, interview questions in the current study focused on an array of experiences, and investigators asked questions that specifically targeted negative, frustrating experiences, as well as possible benefits and positive experiences associated with caring for patients with MUI/S. Third, in previous studies on medical providers' experiences with MUI/S, co-researchers have largely been practicing physicians (e.g., Denz-Penhey & Murdoch, 1993; Fitzgibbon et al., 1997; Gibson & Lindberg, 2011), not residents. Since residents are still immersed in their training programs, where they have resources in the form of mentors and collaborators that can assist them in the care of patients with MUI/S, they may have an increased sense of confidence. Fourth, results may be indicative of a cultural shift occurring in medical school residency education that is more inclusive of teaching about MUI/S and psychosocial aspects of patient care. Finally, many co-researchers commented on the benefits of working with behavioral healthcare providers as part of their medical team, which

could be positively impacting their perceived ability to care for patients with complex issues that may be both biomedical and psychosocial in nature.

Implications for Training

Consistent with residents' reports in this study, other groups of researchers have found that MUI/S is an extremely common complaint seen by primary care providers (Edwards et al., 2010). Thus, medical students and residents could benefit from helpful training tools that focus on MUI/S. Specifically, based on the results of this study, courses in medical school that focus on MUI/S could help providers feel better prepared to work with this group of patients when they join a residency program, regardless of specialization. During residency, contact with patients with MUI/S and structured experience with mentors who express the sentiment "you know sometimes we just don't know" may help increase residents' confidence in treating patients with MUI/S. Furthermore, based on co-researchers' reports that self-growth and introspection are keys to increasing confidence in their work with this group of patients, small group meetings or time that is set aside for residents to discuss their experiences, biases, beliefs, and attributions about MUI/S with mentors, fellow residents, or a combination of both could be helpful self-growth opportunities. Thus, based on these results, a MUI/S training for residents that includes a combination of group exercises, simulated patient exercises, and discussion of residents' own biases and experiences with patients who present with MUI/S may also help to increase their confidence in treating patients who present with MUI/S.

An engaging way to begin a MUI/S training experience, like the one used in this study, is the inclusion of a digitally recorded mock patient/provider interaction. Following this video, an instructor team, ideally consisting of both biomedical and psychosocial providers, could prompt residents to discuss their own biases and beliefs regarding MUI/S, past experiences with patients

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who present with MUI/S, and the attribution they ascribe to MUI/s (e.g., psychosocial, biomedical). Residents could discuss what they have found both frustrating and helpful in their work with this group of patients. Following this discussion, a brief lecture on 'tips' for working with patients who present with MUI/S, from both a biomedical and psychosocial perspective, could commence. Available resources in the clinic and in the community, and how each resource might be helpful in working with MUI/S patients, could be included in the lecture portion of the training. Finally, the training could end with a discussion about how residents plan to utilize available resources and implement what they have learned during the training in their work with their own patients.

Research Implications

Although this study adds to the research about medical providers' experiences caring for patients with MUI/S, additional research on this topic could increase the depth and breadth of understanding about how providers' experiences, beliefs, and attributions regarding MUI/S translate directly into their interactions with patients. Field observation studies could be done to record provider-patient interactions observed during an exam that may impact patient perceptions of their care experience, as well as their intentions to follow the treatment plan. Analyzed interactional sequences and post-exam surveys would help to further hone in on the specific exchanges between provider and patients with MUI/S that impact the patient's feelings of being cared for well.

Future researchers could also study the effectiveness and efficacy of specific medical school and residency program trainings on MUI/S and competencies gained through simulated patient care exercises. Additionally, researchers could create and test programs aimed at helping

residents explore their thoughts and biases about MUI/S in an attempt to increase understanding of how their own internal processes impact patient care.

Healthcare Policy Implications

Based on the results of the systematic review and residents' thoughts expressed during the phenomenological study, providers would be able to become more patient-centered and less frustrated with patients who present with MUI/S if insurers and payers were to change from 'fee-for service' structures to payment structures that focus on performance outcomes. For example, if providers are working in a setting with a 'fee for service' payment structure and are unable to meet MUI/S patients' biomedical and psychosocial needs, the policies governing the treatment protocols and reimbursement structures may need to open up another reimbursement tier for more progressive options. Structures that focus on performance outcomes and that also offer payment for integrated care, complementary medicine, or other specialized testing and treatments may allow all providers, both psychosocial and biomedical, to utilize their expertise, and the expertise of their colleagues, to provide quality patient-centered care. With a collaborative effort between biomedical and psychosocial providers, healthcare policies that reward providing comprehensive patient care could be developed.

The current healthcare climate is in flux. The largest contributor to changes in healthcare is the implementation of the Affordable Care Act (U.S. Department of Health and Human Services, 2013), which aims to help all Americans receive accessible and affordable healthcare insurance. There are other potentially-significant changes pending in health care, such as the goals of the Triple Aim (Institute for Healthcare Improvement, 2013) and the Patient-Centered Medical Home model (Robert Graham Center, 2013), both of which focus on increasing the quality and effectiveness of patient care. Thus, the medical model, with its primary focus on

biomedical components of disease (e.g., Engel, 1977), may be primed for change. Policies that allow for the inclusion of resources that would incorporate a more holistic view of patient and provider experiences, the inclusion of psychosocial aspects of health into diagnosis and treatment, and the addition of integrated care models into standards of practice, could promote more effective patient care.

Broadly, for the needs of MUI/S patients, families, and providers to be effectively met, policy development from the clinical level to the federal level should attend to the biomedical and psychosocial needs of each group. For example, clinic-level policies could include guidelines that encourage physicians to attend frequent trainings and lectures on up-to-date, evidence-based guidelines for MUI/S treatment as well as frequent provider case discussions that include both medical and behavioral health providers. At the federal level, insurance and reimbursement structure policy could encourage the use of quality measures that focus on the patients' and providers' overall wellbeing, instead of relying solely on measures of patients' physical wellbeing. MedFTs should also advocate for policy change that allows for systemically trained therapists, such as licensed marriage and family therapists, to be reimbursed for their services at the state, federal, and private payor levels.

REFERENCES

Asbring, P., & Narvanen, A. L. (2003). Ideal versus reality: Physicians perspectives on patients with chronic fatigue syndrome (CFS) and fibromyalgia. *Social Science & Medicine*, 57, 711-720. doi:10.1016/S0277-9536(02)00420-3

Bieber, C., Muller, K. G., Blumenstiel, K., Schneider, A., Richter, A., Wilke, S., … Eich, W. (2006). Long-term effects of a shared decision-making intervention on physician-patient interaction and outcome in fibromyalgia. A qualitative and quantitative 1 year follow-up of a randomized controlled trial. *Patient Education and Counseling*, *63*, 357-366. doi:10.1016/j.pec.2006.05.003

Borkowski, N. M., & Allen, W. R. (2003). Does attribution theory explain physicians' non acceptance of clinical practice guidelines? *Hospital Topics, 81*(2), 9-21.

Bowen, J., Pheby, D., Charlett, A., & McNulty, C. (2005). Chronic fatigue syndrome: A survey of GPs' attitudes and knowledge. *Family Practice Advance Access*, 22, 389-393. doi:10.1186/147-2296-6-49

Burton, C., McGorm, K., Richardson, G., Weller, D., & Sharpe, M. (2012). Healthcare costs incurred by patients repeatedly referred to secondary medical care with medically unexplained symptoms: A cost of illness study. *Journal of Psychosomatic Research, 72*, 242-247. doi:10.1038/jid.2012.12

Cho, H. J., Menezes, P. R., Bhugra, D., & Wessely, S. (2008). The awareness of chronic fatigue syndrome: A comparative study in Brazil and the United Kingdom. *Journal of Psychosomatic Research*, 64, 351-355. doi:10.1016/j.jpsychores.2007.12.006

Cranford, C., & King, C. R. (2011). Nurse practitioner students' perceptions of fibromyalgia pain and quality of life. *Medsurg Nursing, 20*(4), 169-177.

Denz-Penhey, H., & Murdoch, J. C. (1993). General practitioners acceptance of the validity of

    chronic fatigue syndrome as a diagnosis. *New Zealand Medical Journal, 106*(953), 122-

    124.

Dixon-Woods, M., & Critchley, S. (2000). Medical and lay views of irritable bowel syndrome.

    Family Practice, 17(2), 108-113. doi: 10.1093/fampra/17.2.108

Dumit, J. (2005). Illnesses you have to fight to get: Facts as forces in uncertain,

    emergent illnesses. *Social Science & Medicine, 62*, 577-590.

    doi:10.1016/j.socscimed.2005.06.018

Edwards, T. M., Stern, A., Clarke, D. D., Ivbijaro, G., & Kasney, L. M. (2010). The treatment of

    patients with medically unexplained symptoms in primary care: A review of the

    literature. *Mental Health in Family Medicine, 7*, 209-221.

Fitzgibbon, E. J., Murphy, D., O'Shea, K., & Kelleher, C. (1997). Chronic debilitating fatigue

    in Irish general practice: A survey of general practitioners' experience. *British Journal of*

    General Practice, 47, 618-622.

Gibson, P. R. (2006). *Multiple chemical sensitivity: A survival guide*. Churchville, VA:

    Earthrive Books.

Gibson, P. R., & Lindberg, A. (2011). Physicians' perceptions and practices regarding patient

    reports of multiple chemical sensitivity. *International Scholarly Research Network.*

    Retrieved from http://downloads.ism.com/journals/nursing/2011/838930.pdf.

    doi:10.5402/2011/838930

Hartman, T. C., Hassink-Franke, L. J., Lucassen, P. L., van Spaendonck, K. P., & van Weel, C.

    (2009). Explanation and relations. How do general practitioners deal with patients with

persistent medically unexplained symptoms: A focus group study. *BMC Family Practice,*

10(68). Retrieved from http://www.biomedcentral.com/1471-2296/10/68/.

doi:10.1186/1471-2296-10-68

Hayes, S. M., Myhal, G., Thorton, J. F., Camerlain, M., Jamison, C., Cytryn, K. N., & Murray,

S. (2010). Fibromyalgia and the therapeutic relationship: Where uncertainty meets

attitude. *Pain Resource Management, 15*(6), 385-291.

Lundh, C., Segesten, K., & Bjorkelund, C. (2004). To be a helpless helpoholic – GPs'

experiences of women patients with non-specific muscular pain. *Scandinavian Journal of*

Primary Health Care, 22, 244-247. doi:10.1080/02813430410006756

Martinko, M. J., Harvey, P., & Douglas, S. C. (2007). The role, function, and contribution of

attribution theory to leadership: A review. *The Leadership Quarterly, 18*, 561-585.

doi:10.1016/j.leaqua.2007.09.004

Morse, J. M., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification

strategies for establishing reliability and validity in qualitative research.

International Journal of Qualitative Methods 1(2). Retrieved from

http://www.ualberta.ca/~iiqm/backissues/1_2Final/pdf/morseetal.pdf

Moustakas, C. (1994). *Phenomenological research methods.* Thousand Oaks, CA: Sage.

Patton, M. Q. (2002). *Qualitative research & evaluation methods* (2nd ed.). Thousand Oaks, CA:

Sage.

Phillips, T. (2010). Debating the legitimacy of a contested environmental illness: A case study of

multiple chemical sensitivities (MCS). *Sociology of Health & Illness, 32*(7), 1026-

1040. doi:10.1111/j.1467-9566.2010.01255.x

Reid, S., Whooley, D., Crayford, T., & Hotopf, M. (2001). Medically unexplained

symptoms- GPs' attitude toward their cause and management. *Family Practice,*

   18(5), 519-523. doi:10.1093/fampra/18.5.519

Richardson, R. D., Engel, C. C., McFall, M., McKnight, K., Boehnlein, J. K., & Hunt, S. C.

   (2001). Clinician attributions for symptoms and treatment of Gulf War-related health

   concerns. *Archives of Internal Medicine*, 161, 1289-1294.

   doi:10.1001/archinte.161.10.1289

Robert Graham Center. (2007). *The patient centered medical home: History, seven core features,*

   evidence and transformational change. Retrieved from http://www.graham

   center.org/online/etc/medialib/graham/documents/publications

Stange, K. C., Nutting, P. A., Miller, W. L., Jaen, C. R., Crabtree, B. F., Flocke, S. A., Gill, J. M.

   (2010). Defining and measuring the patient-centered medical home. *Journal of General*

   Internal Medicine, 25, 601-612.

Steven, I. D., McGrath, B., Qureshi, F., Wong, C., Chern, I., & Pearn-Rowe, B. (2000). General

   practitioners' beliefs, attitudes and reported actions towards chronic fatigue syndrome.

   Australian Family Physician, 29, 80-85.

Swanson, L. M., Hamilton, J. C., & Feldman, M. D. (2010). Physician-based estimates of

   medically unexplained symptoms: A comparison of four case definitions. *Family*

   Practice, 27, 487-493.

Swoboda, D. A. (2008). Negotiating the diagnostic uncertainty of contested illnesses:

   Physician practices and paradigms. *Health: An Interdisciplinary Journal for the*

   Social Study of Health, Illness, and Medicine, 12(4), 453-478.

   doi:10.1177/1363459308094420

van Kaam, A. (1959). Phenomenal analysis: Exemplified by a study of the experience of "really

feeling understood." *Journal of Individual Psychology, 15*(1), 66-72.

Weiner, B. (2008). Reflections on the history of attribution theory and research: People,

personalities, publications, problems. *Social Psychology, 39*(3), 151-156.

Figure 1. Attribution Interview Questions.

1. What has been your experience in working with patients who have MUI/S? (experience)

- What are the rewards? (clarifying question)

- What are the challenges? (clarifying question)

2. What are your thoughts or beliefs about MUI/S? (attitude and beliefs)

- What do you believe has influenced these thoughts or beliefs? (clarifying question)

- Can you remember a specific patient, family member, or friend with MUI/S that has shaped your thoughts or beliefs about MUI/S?

- Is there a particular study, article, attending physician, or educational experience that has shaped your thoughts and beliefs about MUI/S?

3. How prepared do you feel you are to work with patients with MUI/S? (understanding)

- What do you think has been helpful in preparing you to diagnose, treat, and mange this group of patients? (clarifying question)

- What do you think would help you feel better prepared to diagnose, treat, and manage this group of patients? (clarifying question)

4. Is there anything you'd like to add about your thoughts or beliefs about MUI/S that we have not covered?

Table 1
Themes and Sub-themes

Theme	Co-Researchers									
	1	2	3	4	5	6	7	8	9	10
1. Medical Education	X	X	X	X	X	X	X	X	X	X
a. Lack of Education	X			X	X	X			X	
b. Helpful Educational Opportunities	X	X	X		X	X	X	X		X
c. Conflicting Information between Medical School and Residency	X	X			X		X			
d. Confidence and Preparedness		X	X		X	X	X	X	X	X
2. Provider and Patient Frustration	X	X	X	X	X	X	X	X	X	X
a. Resident Frustrations	X	X	X	X	X	X	X	X	X	X
b. Patient Frustrations	X	X	X		X	X	X		X	
3. Integrated Care		X	X	X		X	X			X
4. Rewards and Benefits	X	X		X	X	X			X	X
5. Provider/ Patient Relationship		X	X	X	X	X	X	X	X	X
6. Co-Researcher Attributions of MUI/S	X	X	X	X	X	X	X	X	X	X
a. Psychosocial Etiology	X	X	X	X		X	X	X	X	X
b. Combined Etiology	X	X	X		X	X	X	X		X
c. Gaps in Biomedical Knowledge	X			X	X					

*Each X denotes that the co-researcher discussed the corresponding theme during their interview.

Table 2	
Demographics of Co-Researchers (N=10)	
Characteristics	**Value**
Gender	
Males	8 (80%)
Females	2 (20%)
Race	
Hispanic or Latino	1 (10%)
Non-Hispanic White	9 (90%)
Residency Program Type	
Family Medicine	5 (50%)
Internal Medicine	5 (50%)
Rural or Urban Residency	
Rural	4 (40%)
Urban	6 (60%)
Hours of Education on MUI/S	
5 hours or less	5 (50%)
5-10 hours	2 (20%)
10-15 hours	2 (20%)
15-20 hours	0 (0%)
20-25 hours	1 (10%)
Hours of Education on Psychosocial/Mental Health Issues	
5 hours or less	6 (60%)
5-10 hours	2 (20%)
10-15 hours	1 (10%)
20-25 hours	1 (10%)

CHAPTER FIVE: DISCUSSION

Medically unexplained symptoms and medically unexplained illnesses (MUI/S), both of which are commonly characterized by the lack of a definitive biological basis (Dumit, 2005), are the most common complaints seen by primary care providers, with estimates that approximately 25-50 percent of patients seen in primary care present with a MUS (Edwards, Stern, Clarke, & Kasney, 2010). People with either MUS or MUI tend to be higher utilizers of healthcare services and have significantly greater healthcare costs than other patients (Burton, McGorm, Richardson, Weller, & Sharpe, 2012; Reid, Wessely, Crayford, & Hotopf, 2001), which can add stress and strain for the patient, family, provider, and other members of the patient's healthcare team (Gibson, 2006).

This dissertation presented two contributions to the literature on MUI/S. First, a systematic literature review was done that highlighted how medical providers view working with patients who present with MUI/S. Second, a qualitative phenomenological study, based on the gaps in literature found in the systematic review, was completed, which focused on the ways medical residents experience their work with patients with MUI/S. The unifying theory across both studies was Attribution Theory (Heider, 1958). Attribution theory was used to explain why medical providers attributed a variety of causes to patient expression of MUI/S. Psychosocial attributions (e.g., a pessimistic view of life; Asbring & Narvanen, 2003), biomedical attributions (e.g., immune system dysfunction; Denz-Penhey & Murdoch, 1993), and a combination of psychosocial and biomedical factors (e.g., Gibson & Lindberg, 2011; Phillips, 2010) were all reported by providers in the extant literature and in our phenomenological study. Therefore, this dissertation adds to the literature by describing how medical providers view MUI/S and which tools and resources they find helpful to increase confidence and decrease frustration surrounding

their work with this group of patients. The purpose of this discussion chapter is to highlight the outcomes and implications that can be drawn from the research findings presented in this dissertation. The following section includes a description of findings from the systematic review and the phenomenological study.

Study Findings

One of the interesting findings from the systematic review was that experienced providers reported an overall lack of confidence in making diagnostic and treatment decisions (e.g., Bowen, Pheby, Charlett, & McNulty, 2005; Raine, Carter, Sensky, & Black, 2004; Steven et al., 2000), while in our phenomenological study (chapter four) we found that a large majority of residents reported feeling confident and prepared to work with this group of patients. However, regardless of perceived preparedness, both experienced providers and residents expressed frustration when working with patients presenting with MUI/S (e.g., Dixon-Woods & Crichley, 2000; Hayes et al., 2010; Hoedman, Krol, Blankenstein, Koopmans, & Groothoff, 2010). The different levels of confidence reported by practicing physicians and residents in their perceived ability to treat patients with MUI/S may be indicative of the utility of changes in current medical education and residency program structures.

Although the systematic literature review revealed an overall lack of helpful educational opportunities reported by providers, in our qualitative study many helpful educational experiences were reported. Interactions with mentors, education during medical school, and patient contact during residency programs each led to increased confidence in treating patients who presented with MUI/S. Furthermore, providers who participated in this phenomenological study reported feeling relieved when they could utilize resources, such as collaboration with behavioral health professionals or complementary and alternative medicine treatment options, to

assist them in their work with this group of patients. Differences in findings could, again, be the result of changes in medical school and residency education programs that provide opportunities specific to learning about MUI/S, and/or differences may be the result of variations in specific aspects of each study design. For example, in our phenomenological study, we explored the benefits of working with MUI/S patients, as well as educational opportunities residents found helpful. These variables were neglected in previous studies. Examples of helpful opportunities included first-hand experience treating patients with MUI/S, mentorship opportunities, and collaborating with behavioral health professionals. In future studies, asking questions that are inclusive of all experiences, both negative and positive, could contribute to a broader, fuller picture of how providers experience their treatment of patients who present with MUI/S. The following are additional suggestions and implications based on findings from each study that could aid in the development of clinical care programs, impactful research projects, education opportunities, and healthcare policy.

Clinical Implications

In addition to medical providers, the results of this study point to a number of implications for behavioral health (BH) providers. To become effective members of a medical team treating patients with MUI/S, behavioral health providers should gain a base level of understanding regarding the varying difficulties faced by people with MUI/S as well as the possible biomedical and psychosocial components of this group of illnesses. In an attempt to provide less biased, higher quality care, they should also discover their own thoughts, beliefs, and biases surrounding MUI/S and patients who present with these difficulties. With this knowledge base, and attention paid to biases and beliefs, they could take part in informed discussions with the medical team and could add valuable insight about psychosocial aspects of

care to diagnostic and treatment discussions. BH providers also can assist with the provision of direct patient care, focusing on the psychosocial difficulties and strengths present in patients' lives.

More specifically, Medical Family Therapists (MedFTs) may be ideally suited to work with this group of patients and their medical providers. Training for MedFTs is based in systems theory, which indicates that a living system cannot be looked at as a collection of isolated elements. The interactions between the elements create the whole, which is always greater than the sum of its parts (von Bertalanffy, 1950). When applied to medical family therapy, systems theory indicates that therapists must look at the interactions between those in each system instead of solely at the individuals in the system. MedFTs are taught to integrate *into* the medical system to become *part* of the treatment team (McDaniel, Campbell, Hepworth, & Lorenz, 2005). Again, with a focus on the systemic nature of patients' experiences, MedFTs can help patients to discover how they impact and are impacted by the relationships in their lives and their relationship to their physical symptoms.

<center>**Research Implications**</center>

Although the research presented in this dissertation adds to available knowledge on medical providers' experiences of caring for patients with MUI/S, additional research on this topic could increase understanding about how providers' experiences, beliefs, and attributions regarding MUI/S directly translate into their patient interactions. First, greater depth and breadth of understanding providers' experiences of caring for patients with MUI/S is needed if we hope to gain an inclusive picture of how factors such as provider frustration, level of confidence, attribution of illness, and treatment of patients relate to one another. The use of mixed method study designs would help expand what is known about providers' experiences of MUI/s

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(Morgan, 1998) and would allow for greater depth *and* generalizability of findings within the same study.

Another way to develop a more expansive, clearer understanding of the relationships between factors such as provider attribution, diagnostic and treatment practices, frustration, satisfaction with the patient/provider relationship, diagnosis and treatment outcomes, and healthcare costs would be to create a model of how each of these factors impact and are impacted by one another. A model may help explain why some providers become more frustrated or have a more difficult time interacting with MUI/S patients (e.g., Chew-Graham, Cahill, Dowrick, Wearden, & Peters, 2008) than other providers do. This model could help us to identify factors that providers have found helpful in their work with patients with MUI/S. The model should attend to the interplay between psychosocial and biomedical factors that could create a more expansive description of patients presenting with MUI/S and, in turn, allow providers to practice more patient-centered care.

Again, with training in systemic thinking (von Bertalanffy, 1950) and collaboration (McDaniel et al., 2005), MedFTs could create research projects that attend to biomedical and psychosocial needs of both providers and patients. Collaborating on research with patient advocacy organizations that support people with MUI/S would help to ensure that the immediate needs and concerns of the MUI/S patient population are attended to (e.g., Reshelter, Phoenix Rising) in addition to the needs of medical providers. For example, using collaborative efforts, researchers could create a project designed to better understand the experiences of patients, patients' families, and biomedical providers. The design could involve pre and post test measures to discover outcomes for each group, one group using an integrated care model (Blount, 1998), with both biomedical and psychosocial providers, versus a treatment-as-usual model that

includes only biomedical providers. Measures could be developed based on the unique needs of MUI/S patients as reported by patient advocacy groups and found in previously published literature (e.g., Gibson, 2006). Measurements of provider experiences could be based on findings from the systematic review and phenomenology included in this dissertation. Findings from this proposed study could assist in the development of medical school, residency, and continuing education curriculums that are evidence-based and cognizant of needs expressed by patients, patients' families, and providers.

Education and Training Implications

Provider difficulties were discussed in the available literature; however, resources, trainings, and further educational opportunities that providers found helpful were largely neglected. In our qualitative study, providers reported that a number of resources, such as mentorship, patient contact, and self-growth exercises had been helpful in increasing their confidence in working with MUI/S patients. Based on the findings from our interviews with medical residents, additional educational resources that would assist providers in their ability to provide effective care and acquire confidence in their abilities to treat patients with MUI/S need to be developed. Trainings should ideally include a number of components: discussion of providers' biases and beliefs regarding MUI/S, attributions ascribed to MUI/S, and education on biomedical and psychosocial intervention tools.

One recommended training structure, based on the systematic review and the outcomes of the phenomenology study, would be to allow providers the security needed to disclose biases and beliefs they hold about patients who present with MUI/S. With a curriculum that focused on the self-of-provider, participants could learn to better recognize how their internal experiences impact their work with patients and determine how they attribute patient symptoms. Due to the

popularity and accessibility of Internet-based resources and the confidential nature of online programs, a web-based training may be ideal. Another option would be to use a texting service that allows instructors to survey students through text messaging, which would allow students to remain anonymous so that they could respond more honestly to questions about treating MUI/S. Reponses could be tabulated and training extended that is specific to the competencies needed as evidenced through that learning context.

Teaching modules could include evidence-based biomedical and psychosocial interventions for MUI/S, discussions about attributions ascribed to MUI/S, and provider experiences with patients who present with MUI/S. All of these topics could be discussed openly and confidentially using today's technologies and simulated patient resources. Surveys and interviews could be conducted before and after training sessions, so that facilitators could discover helpful modifications for future trainings and develop student learning outcomes that track development of competencies rather than merely checking off that a content area has been taught.

Collaborative efforts between biomedical and psychosocial providers could lead to the development of trainings that have a multi-faceted focus on caring for the whole person. Further, having gained experience with caring for emotional aspects of health for the entire system (e.g., patients, family members, medical providers) during their training experiences, MedFTs may be well-positioned to co-facilitate discussions on how biases and emotional responses impact the provision of effective care for patients with MUI/S.

Healthcare Policy Implications

Based on the results of the systematic review and residents' thoughts expressed during the phenomenological study, providers would be able to become more patient-centered and less

frustrated with patients who present with MUI/S if insurers and payers were to change from 'fee-for service' structures to payment structures that focus on performance outcomes. For example, if providers are working in a setting with a 'fee for service' payment structure and are unable to meet MUI/S patients' biomedical and psychosocial needs, the policies governing the treatment protocols and reimbursement structures may need to open up another reimbursement tier for more progressive options. Structures that focus on performance outcomes and that also offer payment for integrated care, complementary medicine, or other specialized testing and treatments may allow all providers, both psychosocial and biomedical, to utilize their expertise, and the expertise of their colleagues, to provide quality patient-centered care. With a collaborative effort between biomedical and psychosocial providers, healthcare policies that reward providing comprehensive patient care could be developed.

The current healthcare climate is in flux. The largest contributor to changes in healthcare is the implementation of the Affordable Care Act (U.S. Department of Health and Human Services, 2013), which aims to help all Americans receive accessible and affordable healthcare insurance. There are other potentially-significant changes pending in health care, such as the goals of the Triple Aim (Institute for Healthcare Improvement, 2013) and the Patient-Centered Medical Home model (Robert Graham Center, 2013), both of which focus on increasing the quality and effectiveness of patient care. Thus, the medical model, with its primary focus on biomedical components of disease (e.g., Engel, 1977), may be primed for change. Policies that allow for the inclusion of resources that would incorporate a more holistic view of patient and provider experiences, the inclusion of psychosocial aspects of health into diagnosis and treatment, and the addition of integrated care models into standards of practice, could promote more effective patient care.

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REFERENCES

Asbring, P., & Narvanen, A. L. (2003). Ideal versus reality: Physicians perspectives on patients with chronic fatigue syndrome (CFS) and fibromyalgia. *Social Science & Medicine*, 57, 711-720. doi:10.1016/S0277-9536(02)00420-3

Blount, A. (1998). *Integrated primary care: The future of medical and mental health collaboration*. New York, NY: Norton.

Bowen, J., Pheby, D., Charlett, A., & McNulty, C. (2005). Chronic fatigue syndrome: A survey of GPs' attitudes and knowledge. *Family Practice Advance Access*, 22, 389-393. doi:10.1186/147-2296-6-49

Burton, C., McGorm, K., Richardson, G., Weller, D., & Sharpe, M. (2012). Healthcare costs incurred by patients repeatedly referred to secondary medical care with medically unexplained symptoms: A cost of illness study. *Journal of Psychosomatic Research, 72*, 242-247. doi:10.1038/jid.2012.12

Chew-Graham, C. A., Cahill, G., Dowrick, C., Wearden, A., & Peters, S. (2008). Using multiple sources of knowledge to reach clinical understanding of chronic fatigue syndrome. *Annals of Family Medicine, 6*(4), 340-348. doi:10.1370/afm.867

Denz-Penhey, H., & Murdoch, J. C. (1993). General practitioners acceptance of the validity of chronic fatigue syndrome as a diagnosis. *New Zealand Medical Journal, 106*(953), 122-124.

Dixon-Woods, M., & Critchley, S. (2000). Medical and lay views of irritable bowel syndrome. *Family Practice, 17*(2), 108-113. doi: 10.1093/fampra/17.2.108

Dumit, J. (2005). Illnesses you have to fight to get: Facts as forces in uncertain,

emergent illnesses. *Social Science & Medicine, 62*, 577-590.

doi:10.1016/j.socscimed.2005.06.018

Edwards, T. M., Stern, A., Clarke, D. D., Ivbijaro, G., & Kasney, L. M. (2010). The treatment of

patients with medically unexplained symptoms in primary care: A review of the

literature. *Mental Health in Family Medicine, 7*, 209-221.

Engel, G. L. (1977). The need for a new medical model: A challenge for biomedicine. *Science,*

196, 129-136.

Gibson, P. R. (2006). *Multiple chemical sensitivity: A survival guide*. Churchville, VA:

Earthrive Books.

Gibson, P. R., & Lindberg, A. (2011). Physicians' perceptions and practices regarding patient

reports of multiple chemical sensitivity. *International Scholarly Research Network.*

Retrieved from http://downloads.ism.com/journals/nursing/2011/838930.pdf.

doi:10.5402/2011/838930

Hayes, S. M., Myhal, G., Thorton, J. F., Camerlain, M., Jamison, C., Cytryn, K. N., & Murray,

S. (2010). Fibromyalgia and the therapeutic relationship: Where uncertainty meets

attitude. *Pain Resource Management, 15*(6), 385-291.

Heider, F. (1958). *The psychology of interpersonal relations*. New York, NY: Wiley.

Hoedeman, R., Krol, B., Blankenstein, A. H., Koopmans, P. C., & Groothoff, J. W. (2010).

Sick-listed employees with severe medically unexplained physical symptoms: Burden or

routine for the occupational health physician? A cross sectional study. *BMC Health*

Services Research, 10, 305-312. doi:10.1186/1472-6963-10-305

Institute for Healthcare Improvement (2013). *The IHI triple aim*. Retrieved from

http://www.ihi.org/offerings/Initiatives/TripleAim/Pages/default.aspx

McDaniel, S. H., Campbell, T. L., Hepworth, J., & Lorenz, A. (2005). *Family-oriented primary care (2nd ed.)*. New York, NY: Springer.

Morgan, D. L. (1998). Practical strategies for combining qualitative and quantitative methods: Applications to health research. *Qualitative Health Research, 8*, 362-376. doi:10.1177/104973239800800307

Phillips, T. (2010). Debating the legitimacy of a contested environmental illness: A case study of multiple chemical sensitivities (MCS). *Sociology of Health & Illness, 32*(7), 1026-1040. doi:10.1111/j.1467-9566.2010.01255.x

Raine, R., Carter, S., Sensky, T., & Black, N. (2004). General practitioners' perceptions of chronic fatigue syndrome and beliefs about its management, compared with irritable bowel syndrome: Qualitative study. *British Medical Journal*, 328, 1354-1356. doi:10.1136/bmj.38078.503819.EE

Reid, S., Whooley, D., Crayford, T., & Hotopf, M. (2001). Medically unexplained symptoms- GPs' attitude toward their cause and management. *Family Practice, 18*(5), 519-523. doi:10.1093/fampra/18.5.519

Robert Graham Center (2013). *The patient centered medical home*. Retrieved from http://www.graham-center.org/PreBuilt/PCMH.pdf

Steven, I. D., McGrath, B., Qureshi, F., Wong, C., Chern, I., & Pearn-Rowe, B. (2000). General practitioners' beliefs, attitudes and reported actions towards chronic fatigue syndrome. *Australian Family Physician, 29*, 80-85.

Ullman, J. B. (2006). Structural equation modeling: Reviewing the basics and moving forward. *Journal of Personality Assessment, 87*(1), 35-50. doi:10.1207/s15327752jpa8701_03

U.S. Department of Health and Human Services (2013). *Key features of the Affordable Care*

Act, by year. Retrieved from http://www.healthcare.gov/law/timeline/full.html

von Bertalanffy, L. (1950). An outline of general systems theory. *The British Journal for the Philosophy of Science, 1*(2), 134-165.

APPENDIX A: IRB APPROVAL

EAST CAROLINA UNIVERSITY
University & Medical Center Institutional Review Board Office
4N-70 Brody Medical Sciences Building· Mail Stop 682
600 Moye Boulevard · Greenville, NC 27834
Office **252-744-2914** · Fax **252-744-2284** · **www.ecu.edu/irb**

Notification of Initial Approval: Expedited

From: Social/Behavioral IRB
To: Jennifer Harsh
CC: Jennifer Hodgson
Date: 12/6/2012
Re: UMCIRB 12-002113
        Medical Residents' Views of Medically Unexplained Illness and Medically Unexplained Symptoms

I am pleased to inform you that your Expedited Application was approved. Approval of the study and any consent form(s) is for the period of 12/6/2012 to 12/5/2013. The research study is eligible for review under expedited categories #6 and #7. The Chairperson (or designee) deemed this study no more than minimal risk.

Changes to this approved research may not be initiated without UMCIRB review except when necessary to eliminate an apparent immediate hazard to the participant. All unanticipated problems involving risks to participants and others must be promptly reported to the UMCIRB. The investigator must submit a continuing review/closure application to the UMCIRB prior to the date of study expiration. The Investigator must adhere to all reporting requirements for this study.

The Chairperson (or designee) does not have a potential for conflict of interest on this study.

RB00000705 East Carolina U IRB #1 (Biomedical) IORG0000418
IRB00003781 East Carolina U IRB #2 (Behavioral/SS) IORG0000418 IRB00004973

APPENDIX B: SURVEY

Demographic Information

1. What year were you born? _____

2. What is your gender? _____

3. How do you describe yourself (select all that apply)?

- American Indian or Alaska Native ☐

- Hawaiian or Other Pacific Islander ☐

- Asian or Asian American ☐

- African American ☐

- Black ☐

- Hispanic or Latino ☐

- Non-Hispanic White ☐

- Other (Please Explain) _____

4. What is your residency program type and name?

- Name: _____

- Type: Family Medicine ☐   Internal Medicine ☐

5. Where is the location of residency program? _____ (City)

_____ (State)

_____ (Country)

6. Where did you attend medical school?   _____ (Name of medical school)

_____ (Location of medical school)

7. For the majority of your residency education, have you worked more with patients from an urban or a rural setting?

- Rural ☐

- Urban ☐

8. How many hours of education have you had on medically unexplained symptoms or medically unexplained illnesses (MUI/S; e.g., chronic fatigue syndrome, diffuse chronic pain)?

- 5 hours or less ☐

- 5-10 hours ☐

- 10-15 hours ☐

- 15-20 hour ☐

- 20-25 hours ☐

- Other: _____ hours

9. How may hours of education have you had on psychosocial/mental health?

- 5 hours or less ☐

- 5-10 hours ☐

- 10-15 hours ☐

- 15-20 hour ☐

- 20-25 hours ☐

- Other: _____ hours

10. Where have you learned the majority of the information you know about MUI/S? Please place a percentage that reflects each category in the blank space behind each category and please explain the type of learning experience you've had for each applicable category (e.g. Media: 20%, Please explain: via documentaries and television programs).

- Medical school ☐ _____ Please explain: _____

- Residency education ☐ _____ Please explain: _____

- Workshops or trainings ☐_____ Please explain: _____

- Media ☐_____ Please explain: _____

- Other: Please explain: _____

11. Do you know anyone personally with MUI/S?

- No ☐

- Yes ☐

  o If so, how do you know this person? _____

  o Please share up to three symptoms you have recognized in this person.

  _____

12. Thus far in your medical career, approximately how many patients have you cared for with MUI/S?

- 1- 5 patients ☐

- 5-10 patients ☐

- 10-25 patients ☐

- 25-50 patients ☐

- 50-75 patients ☐

- 75+ patients ☐

13. What percentage of the patients with MUI/S that you have cared for (from question #12) were over the age of 18? _____

APPENDIX C: VIDEO VIGNETTE

Video Vignette of Provider/Patient Interaction

Provider: The provider will introduce himself to the patient and begin the encounter by asking her about what brings her in today.

Patient: The patient presents with headaches, abdominal pain, and constipation. The headaches began about 18 years ago, which was about the same time the patient changed her job. The abdominal pain began15 years ago, which she recalls because it was right around the time she and her husband were married. Her headaches are her biggest complaint since they come and go for no apparent reason and they become so severe that she cannot complete her daily tasks.

Provider: The provider will ask about any treatments the patient has tried in the past.

Patient: She has tried increasing the fiber in her diet, which does not help. She has used enemas for many years and has had occasional relief. She has tried pain medication to no avail.

Provider: The provider asks her about the emergency room visits that have shown up in her electronic medical record.

Patient: She has visited the emergency room 10 times in the past 6 months when her headaches or bowel symptoms became debilitating.

Provider: The provider will ask if she has a history of any other difficulties.

Patient: She has had intermittent depressive symptoms for about 18 years and she has been on a number of anti-depressant medications, prescribed by previous primary care physicians, which have relieved some of her depressive symptoms, but have not had an impact on her physical symptoms. She is tired of her physicians telling her that her physical symptoms stem from her depression. She is very leery of doctors since she has not experienced much relief for her

physical symptoms from any treatments and she feels like her past providers have thought she

was 'crazy'.

REFERENCES

Dwamena, F. C. (2007). *Treating medically unexplained symptoms: An evidence-based method*

[PDF document]. Retrieved from Society of General Internal Medicine Website:

http://www.sgim.org/

APPENDIX D: GUIDE

Interview Guide

Over the next few minutes I will show you a case vignette video of an interaction between a medical provider and patient. I will ask you follow up questions pertaining to the case vignette presented in the video. I will then ask you an additional series of questions regarding your experience, thoughts, and beliefs surrounding medically unexplained illness and medically unexplained symptoms (MUI/S). Please share anything with me that you are comfortable sharing. If you feel uncomfortable answering any of the questions, please let me know and we will move on to the next question. Do you have any questions before we begin?

Video Vignette Questions

Interview Questions:

1. What is your first reaction to this patient/provider interaction?

2. What do you believe is causing this patient's symptoms? Why?

3. How would you diagnose this patient?

- What additional resources or referrals may be helpful in diagnosing or treating this patient? (clarifying question)

4. What would you include in this patient's treatment plan?

- What additional information, if any, do you need? (clarifying question)

5. What have you learned in your medical education, including your time in medical school and your residency program that has helped you treat this type of patient?

Attribution Interview Questions

Interview Questions:

1. What has been your experience in working with patients who have MUI/S? (experience)

- What are the rewards? (clarifying question)

- What are the challenges? (clarifying question)

2. What are your thoughts or beliefs about MUI/S? (attitude and beliefs)

- What do you believe has influenced these thoughts or beliefs? (clarifying question)

- Can you remember a specific patient, family member, or friend with MUI/S that has shaped your thoughts or beliefs about MUI/S?

- Is there a particular study, article, attending physician, or educational experience that has shaped your thoughts and beliefs about MUI/S?

3. How prepared do you feel you are to work with patients with MUI/S? (understanding)

- What do you think has been helpful in preparing you to diagnose, treat, and mange this group of patients? (clarifying question)

- What do you think would help you feel better prepared to diagnose, treat, and manage this group of patients? (clarifying question)

4. Is there anything you'd like to add about your thoughts or beliefs about MUI/S that we have not covered?

APPENDIX E: CORRESPONDENCE

Co-Researcher Recruitment Email

Dear Medical Resident:

I am inviting you to participate in a study, in which researchers will seek to better understand medical residents' thoughts and beliefs surrounding medically unexplained symptoms and medically unexplained illnesses. Your participation in this research study will help me better understand this topic and may assist in the future development of educational opportunities and resources to better assist medical providers in effectively and confidently providing care to patients with these medical difficulties.

Participation will involve an interview conducted via Skype, an online videoconferencing program, at a time that is convenient for you. The interview will take approximately 30 minutes to complete. Your responses to interview questions will be kept confidential and a pseudonym will be used to protect your identity. You are also able to terminate participation at any time without any negative repercussions. As a token of appreciation for your participation, a $20 gift card will be provided. The information gained from your interview and those of other participants will be used to complete my dissertation and will contribute to the growing body of knowledge on medical providers' views of medically unexplained symptoms and medically unexplained illness.

If you have any questions about this study, please contact me at harshj10@students.ecu.edu or (808) 778-7253. You may also feel free to contact my research supervisor Jennifer Hodgson, PhD, LMFT, at Hodgsonj@ecu.edu or (252) 328-1349.

Thank you for your time,

Jennifer Harsh, MA

PhD Candidate

East Carolina University

Primary Investigator

Jennifer Hodgson, PhD, LMFT

Professor

East Carolina University

Research Supervisor

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APPENDIX F: INFORMED CONSENT

Informed Consent to Participate in Research

East Carolina

University

EAST CAROLINA UNIVERSITY
University & Medical Center Institutional Review Board Office
4N-70 Brody Medical Sciences Building· Mail Stop 682
600 Moye Boulevard · Greenville, NC 27834
Office **252-744-2914** · Fax **252-744-2284** · **www.ecu.edu/irb**

Title of Research Study: Medically Unexplained Illness and Medically Unexplained Symptoms: Medical Residents' Thoughts, Beliefs, and Attributions

Principal Investigator: Jennifer Harsh, MA, Doctoral Candidate, East Carolina University

Research Supervisor: Jennifer Hodgson, PhD, LMFT, East Carolina University

Institution/Department or Division: Department of Child Development and Family Relations

Address: 130 Rivers Building, Greenville, NC 27858

Telephone: 808-778-7253

_____

Why is this research being done?
The purpose of this research is to gain a better understanding of medical residents' experiences, thoughts, beliefs, and attributions surrounding medically unexplained symptoms and medically unexplained illness (MUI/S). The decision to take part in this research is yours to make. By doing this research, we hope to learn how providers perceive and experience the provision of medical care to patients with MUI/S.

Why am I being invited to take part in this research?
You are being invited to take part in this research because you are a third-year medical resident who has worked with patients that have presented with MUI/S. If you volunteer to take part in this research, you will be one of about 12 people to do so nationally.

Are there reasons I should not take part in this research?
You should not volunteer for this study if you are not a third-year medical resident or if you have not provided care for any patients who have presented with MUI/S.

What other choices do I have if I do not take part in this research?
You can choose not to participate in this research study.

Where is the research going to take place and how long will it last?

The research procedures will be conducted via Skype and via an online survey program at a time of your choosing. The total amount of time you will be asked to volunteer for this study is approximately 30 minutes.

What will I be asked to do?
You are being asked to do the following: Fill out a demographic survey in an online survey program and participate in an individual, in-depth interview via Skype. During the interview, you will be also be asked to view a short video vignette and then respond to questions based on the provider/patient interaction you see in the video. The interview will be scheduled at a mutually convenient time within the next 30 days. Interview questions will be related to your experience working with patients with MUI/S, your training surrounding MUI/S, and the meaning you ascribe to working with this group of patients.

What possible harms or discomforts might I experience if I take part in the research?
It has been determined that the risks associated with this research are no more than what you would experience in everyday life. It is possible that you may experience some discomfort during the interview if the interview questions lead you to recall uncomfortable experiences or situations.

What are the possible benefits I may experience from taking part in this research?
This research may help us learn more about medical residents' experience, thoughts, and ideas surrounding MUI/S. However, there may be no personal benefit from your participation, but the information gained by doing this research may help others caring for those with MUI/S in the future.

Will I be paid for taking part in this research?
We will not be able to pay you for the time you volunteer while being in this study. However, you will receive a $20 gift certificate for volunteering your time.

What will it cost me to take part in this research?
It will not cost you any money to be part of the research. It will cost you approximately 30 minutes of your time.

Who will know that I took part in this research and learn personal information about me?
Every attempt will be made to maintain your confidentiality during and after the study. As part of maintaining confidentiality, a false name or a non-related number will identify you. Only the research team will view all information. Only the primary investigator will know your actual name. Your actual name and other identifying information will not be used in connection with any data reported from this study. Your actual name will also never be used in any presentation or publications of the study results.

How will you keep the information you collect about me secure? How long will you keep it?

With your permission, the investigator will take typewritten notes during the interview and the interview will be audio recorded for the purpose of documenting your experiences and perspectives accurately. The investigator will then transcribe the audio recording verbatim. Per ECU guidelines, all data will be retained by the researcher's supervisor in a password-protected computer for a period of three years at ECU, at which point the materials associated with the study will be deleted or destroyed. Your name will not be used in the transcription of the recording or the research findings since the investigator will replace your name with a pseudonym or non-related number. In addition, all identifying information related to you and the institution with which you are affiliated will be changed in the transcription and the final report of findings. Information learned from the interview may be used in presentations or in future research without identifying you as a research participant.

What if I decide I do not want to continue in this research?
If you decide you no longer want to be in this research after it has already started, you may stop at any time. You will not be penalized or criticized for stopping your participation.

Who should I contact if I have questions?
The people conducting this study will be available to answer any questions concerning this research, now or in the future. You may contact the Principal Investigator, Jennifer Harsh, by phone at (808) 778-7253 or by email at harshj10@students.ecu.edu. You may also contact the research supervisor, Jennifer Hodgson, at (252) 328-1349 or by email at hodgsonj@ecu.edu.

If you have questions about your rights as someone taking part in research, you may call the Office for Human Research Integrity (OHRI) at phone number 252-744-2914 (days, 8:00 am-5:00 pm). If you would like to report a complaint or concern about this research study, you may call the Director of the OHRI, at 252-744-1972.

I have decided I want to take part in this research. What should I do now?
The person obtaining informed consent is asking you to read the following and if you agree, you should sign this form electronically by marking 'yes, I agree to participate'. If you do not agree, please mark 'no, I do not agree to participate'.

- I have read (or had read to me) all of the above information.
- I have had an opportunity to ask questions about things in this research I did not understand and have received satisfactory answers.
- I know that I can stop taking part in this study at any time.
- By signing this informed consent form, electronically, I am not giving up any of my rights.

☐ Yes, I agree to participate
☐ No, I do not agree to participate

APPENDIX G: BIAS STATEMENT

Primary Investigator Bias Statement

As a person who has been living with multiple chemical sensitivities, a medically unexplained illness, for many years, and as a behavioral health provider working in multiple medical settings, I have a number of biases and assumptions about medical providers and their attitudes and beliefs surrounding medically unexplained illnesses and medically unexplained symptoms (MUI/S). These assumptions and biases include:

- Many medical providers believe patients with MUI/S have symptoms that can be better explained by psychosocial, rather than biomedical etiology.

- Many medical providers experience frustration while working with patients with MUI/S.

- It is unpopular among the medical community to believe that MUI/S may be biomedical in nature, and it is unpopular to believe that biomedical technology is simply not yet advanced enough to fully understand the etiology of MUI/S.

- I believe many medical providers discuss patients with MUI/S in a negative manner with their colleagues.

- I believe that, through the proposed study, I may find that medical residents will not have had more than a few hours of education regarding MUI/S.

- I believe that, through the proposed study, I may find that medical residents believe that working with patients who present with MUI/S will be time consuming and frustrating.

- I assume that medical residents will report mixed attributions regarding the etiology of MUI/S, but I assume psychosocial attributions will be the attribution most largely represented.