Ethical Communication of the Unexplainable: Examining Primary Care for Patients with Medically Unexplained Symptoms

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Abstract

Medically unexplained symptoms (MUS) are persistent physical symptoms that cannot be satisfactorily explained by organic changes, nor attributed to psychoactive drug use. MUS are highly prevalent in primary care: nearly 50% of patients complain of at least one, according to a 2015 review. While most Primary Care Physicians (PCPs) feel that these symptoms should be managed in primary care, many are challenged and frustrated by patients with MUS and find it difficult to provide them with good quality care. Patients with MUS have lower satisfaction with their clinical encounters and often feel rejected by their PCPs. This project endeavours to address these issues by exploring how PCPs communicate with patients regarding their MUS and the ethical, conceptual and practical issues surrounding this communication.

Chapter One explores the conceptual and practical challenges related to communicating about MUS. These include the difficulty in reaching a shared understanding of symptoms between patient and physician within the traditional biomedical ontology in the absence of a medical explanation, the lack of evidence of a causal pathology for the symptoms and the impossibility of proving the absence of a cause, and the implicit dualism dividing "real medical problems" from psychological ones.

The second chapter interrogates three foci of communication about MUS in the clinical encounter via a critical interpretive review: 1. The beliefs of patients with MUS regarding the nature of their symptoms, 2. The ways patients express their beliefs and desires for care, and 3. How GPs communicate with patients and respond to their requests and expressed needs. Patients with MUS were found to have multiple, complex explanations for their symptoms that often include psychological and social causes, to often suggest or directly express a desire for their PCP to engage with psychosocial issues they are facing, and to make requests for explanations, empathetic listening, and honest communication from their PCPs. PCPs frequently respond with non-specific reassurance, normalisations and explanations that do not engage with patients' own explanations and expressed concerns.

Chapter Three expands upon the conceptual and practical problems with MUS to highlight specific ethical difficulties in caring for patients with MUS. I posit that patients with MUS suffer a unique and salient burden of epistemic injustice, owing to a number of related issues, notable

among which, the view that a misunderstanding of bodily sensations is an essential quality of MUS. From these epistemic harms emerge several more tangible harms, including iatrogenic searches for elusive explanations, and those resulting from overtreatment and lack of access to appropriate care. Issues of informed consent and justice in access to care are discussed.

Chapter Four offers a novel approach to communicating about MUS, particularly to explaining the symptoms in primary care. Drawing from Stilwell and Harman’s enactive approach to pain, Havi Carel’s phenomenological toolkit, and a pragmatic, prospective, causally pluralistic approach to explanation, this new, more ethical and patient-centered method of explanation is elaborated.

Résumé

Les symptômes médicalement inexpliqués (SMIs) sont des symptômes physiques persistants, qui ne peuvent être expliqués de manière satisfaisante par des changements organiques, ni attribués à l'utilisation de drogues psychotropes. Les SMIs sont très communs : presque la moitié des patients visitant leurs médecins omnipraticiens se plaignent d'au moins un SMI, selon une revue datant de 2015. Alors que la majorité des médecins omnipraticiens se croient responsables de gérer ces symptômes, ils trouvent ces patients frustrants et ils ont de la difficulté à leur offrir des soins adéquats. Les patients avec SMIs, de leur part, sont moins satisfaits par leurs soins médicaux et se sentent souvent rejetés par leurs médecins. Ce projet tente d'adresser ces problèmes en examinant et faisant l'analyse éthique de la communication entre les médecins omnipraticiens et leurs patients avec SMIs.

Dans le premier chapitre, les problèmes conceptuels et pratiques liés à la communication à propos des SMIs seront élaborés, y compris le manque d'explication pour les symptômes dans l'ontologie biomédicale traditionnelle, l'impossibilité d'établir avec preuve que les symptômes n'ont pas de cause et la dichotomie entre ce que l'on considère de vrais problèmes médicaux et ce qui ne le sont pas. Les liens entre ces problèmes et les difficultés dans la communication entre le patient et le médecin sont discutés.

Chapitre deux examine cette communication avec une revue critique de la littérature sur les SMIs. Trois questions guident cette revue : Quelles sont les croyances des patients avec SMIs quant à la nature de leurs symptômes ? Comment expriment ces patients leurs croyances et leurs attentes de leurs médecins quant à leurs soins médicaux ? Comment les médecins omnipraticiens communiquent-ils avec les patients avec SMIs et comment répondent-ils aux demandes et aux besoins de ces patients ? Ces patients ont souvent des explications complexes pour leurs symptômes qu'ils expriment à leurs médecins. Ils demandent souvent des explications, de l'écoute et de la communication honnête de leurs médecins et les médecins répondent fréquemment avec la réassurance non-spécifique et des explications qui ne s'engagent pas avec les besoins et les soucis des patients.

Chapitre trois examine les difficultés éthiques liées aux soins des patients avec SMIs. Je suggère que les patients avec SMIs souffrent d'un fardeau saillant et particulier d'injustice

épistémique, lié notamment à la qualité particulière des SMIs qui dit qu'une fausse interprétation et compréhension des expériences corporelles est une qualité essentielle des SMIs. De ces injustices épistémiques sortent d'autres dommages, notamment le processus iatrogène de la quête pour une explication pour les symptômes, le surtraitement et l'inaccessibilité de soins médicaux dans l'absence d'une explication médicale pour les symptômes.

Dans le dernier chapitre, j'offre une nouvelle approche collaborative et centrée sur le patient pour construire des explications acceptables, éthiques et justes pour les symptômes. Cette méthode emploie la phénoménologie, une compréhension « enactive » de la douleur et une approche pragmatique et pluraliste aux explications, afin d'améliorer la communication entre les patients avec SMIs et leurs médecins ainsi que les soins offerts à ces patients.

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Contribution of Authors

Tamara Perez was the primary author of all chapters of this thesis, responsible for conceiving the project, all research, analysis, and writing. She was supervised by Dr. Carolyn Ells who read her work and provided feedback on content and structure.

Legend

BPS: Biopsychosocial
CAI: Causal Attributions Interview
CMA: Canadian Medical Association
EBM: Evidence-based medicine
GERD: Gastroesophageal reflux disease
GP: General practitioner
IPQ: Illness Perception Questionnaire
LBP: Low back pain
LCIAS: Liverpool Clinical Interaction Analysis Scheme
MUPS: Medically unexplained physical symptoms
MUS: Medically unexplained symptoms
PCC: Patient-Centered Care
PCP: Primary care provider
SEMI: Short Explanatory Model Interview
SMIs: Symptômes médicalement inexpliqués

Chapter 1: Introduction

Medically Unexplained Symptoms – A Terminological, Practical and Clinical Challenge

This thesis examines the care of patients with medically unexplained symptoms (MUS). As an organizational construct rather than a diagnosis, MUS broadly denotes all symptoms for which a causative explanatory pathology cannot be identified. These pose a particular problem in medical practice for several reasons, generally stemming from the lack of clear medical explanation for the symptoms, and the unresolved ethical questions regarding how to appropriately care for these patients. In this first chapter, I elaborate upon the concept of medically unexplained symptoms and outline the background and rationale for my thesis, discussing the conceptual and theoretical problems that MUS pose, and how these issues translate to practical challenges in the care for patients with MUS.

Part A: Meaning-Making in Illness and the Biomedical Model

Most patients seek medical care because of both the severity of symptoms they experience and concern over the meaning or threat that the symptoms represent. (1) Both reasons indicate the presence of illness, which Per Sundström describes as the individual's subjective feeling that all is not well with their body and their self. (2) Illness is a fundamentally and intimately personal experience, in which one's habitual ways of interacting with the world and the unity between self and body are disrupted. (3) Illness is a chaotic disturbance (3); and embodied suffering is ever-present or all-consuming, confining one to the present moment and its demands, threatening the future. It is this interruption and feeling of uncanniness, alienation from one's body (4) that is appraised as threatening, and which pushes one to search for meaning in illness. The process of appraising bodily experiences as threatening and understanding them as symptoms of an illness is one element of meaning-making, as described by Merleau-Ponty. (5)

The clinician can play an important role in this meaning-making process, using their technical expertise on the functioning of the body to identify the process causing the suffering and subsequently treat the underlying pathology or address the symptoms to alleviate the patient's suffering and relieve them of their illness. The role of the physician may be understood as that of an interpreter of the language of bodily experiences, (2,6) and for them to do so with any degree of reliability, they must encourage the patient's subjective account of their illness and strive to understand it through dialogue with the patient. Within the biomedical clinical encounter, the physician collects the information provided by the patient when they recount the history of their illness. With this information, combined with the physical examination and the results of any investigations, they can determine an appropriate diagnosis that can be used to guide treatment. This approach addresses the patient's need to make sense of their symptoms, while also using the clinical information collected to address the symptoms through treatment of disease, defined as the abnormalities of the structure and function of body organs and systems, (7) its deviation from normal defined by reference to anatomical, physiological and biochemical parameters. (8) Illness, or the abnormality as it is felt by the patient, the subjective response of an individual to being unwell, and the significance attributed to this (8–11) may be addressed through the alleviation of symptoms secondary to the treatment of disease. The illness experience itself is rarely the centre of the patient-physician interaction within a medical model that focuses on the identification and treatment of disease and assumes a causal relationship between disease and illness (based in the assumption that all illnesses and symptoms are due to underlying abnormalities and that all disease gives rise to symptoms). (12)

This notion that illness is necessarily the experiential manifestation of an underlying pathological process is at the basis of the biomedical model, which operates according to a reductionist framework, in which all illness and symptoms are understood to arise from an underlying abnormality within the body, and that all diseases give rise to symptoms. (12) This dominant model originates from Virchow's conclusion that all disease results from cellular abnormalities. (12,13) This conventional clinical method of healthcare reflects an ontological model of disease, and while this method of biomedicine, which serves primarily to prevent death through the treatment of disease, has been largely successful at doing just that, it remains inadequate in addressing illness and managing chronic diseases. (14) This approach, in which disease is the phenomenological and conceptual centre of practical-clinical medicine (2), means that symptoms that exist in the absence of identifiable disease or objectifiable abnormality are a challenge to address. The biopsychosocial (BPS) model, introduced by George Engel, attempted to rectify the shortcomings of the biomedical model through a more holistic approach to medicine, attempting to incorporate the biological, psychological, and social realms of the patient's lived experience. (15,16) Though this allowed for the consideration of other elements of the patient's life that may be contributing to symptoms, it remains essentially mechanistic and dualistic, and nonetheless excludes the centrality of the patient's experience of illness (17) and fails to offer a methodology to consider these elements systematically in clinical practice. (18) The patient-centered clinical method offers an approach to centering the patient's experience in the clinical encounter, seeking to attain an integrated understanding of the patient's illness, their concept of health, and find common ground between patient and clinician. (19) It is an approach to patient care that values the patient's unique expertise over their experience, and, as will be elaborated in later chapters, may be more suited to addressing MUS.

Part B: Introducing Medically Unexplained Symptoms

MUS represent a noteworthy and paradigmatic example of the shortcomings of the biomedical model, demonstrating the limitations of evidence-based medicine (20–22) through our lack of medical understanding of the symptoms and failure to find generalizable causal explanations to account for the diversity of experiences of MUS. These are persistent physical symptoms that cannot be satisfactorily explained by organic changes, nor attributed to psychoactive drug use. (23–25) The term "MUS" is one of many used to refer to symptoms or illnesses experienced by individuals, for which they seek medical attention but for which no clear pathophysiological process or organic change can be identified to explain the bodily experience.

Estimates for prevalence of MUS in primary care often figure in the range of 20%, (26,27) and a recent review estimates that they account for 10-15% of all general practice consultations. (28) It is reported that nearly 50% of patients in primary care complain of at least one medically unexplained symptom, (29) and rates are as high as 52% in a study across seven specialties. (30) The literature on MUS is rather heterogenous, in part due to inconsistent terminology and criteria for symptoms to be deemed medically unexplained. It is likely that most people, at some point, will experience symptoms for which there is no clear medical explanation, though not all will seek medical attention or have the symptoms labelled as "medically unexplained".

This information effectively frames the problem of MUS: they are remarkably prevalent, they pose an epistemological problem due to their lack of causal explanations and meaningful diagnostic criteria, (31) which translates into care that is not responsive to patients' needs. (32,33) This inadequate care for patients with MUS is multifactorial: The preponderance of evidence indicates that patients with MUS are not receiving care that is responsive to their needs and desires, (34–36) and may receive unindicated somatic interventions that they do not benefit from nor want, (32,37) are provided with explanations that do not engage with their understanding or worries about their symptoms, (32,34,38) and often feel rejected by their physician. (34,39) Despite most general practitioners (GPs) feeling that these symptoms should be managed in primary care, (40) many are challenged and frustrated by patients with MUS (41) and find it difficult to provide good quality care to these patients. (42,43)

Within the biomedical model of healthcare, in which disease is the phenomenological and conceptual centre of practical-clinical medicine, (2) MUS are inherently problematic and disruptive to the standard clinical consultation precisely because the symptoms do not have a clear etiology and do not correspond to objectifiable disease. This is borne out in inadequate care for patients that is unresponsive to their needs and may contribute to somatization, shaping patients' symptoms, causing them to focus somatically and perform the sick role to become a 'credible patient' (44) and potentially exacerbating their illness. (45)

This thesis is a study of medical care for patients with MUS in the primary care setting, focusing on the role and the methods of communication about patients' symptoms. While many patients with persistent MUS are eventually referred to a specialist and followed in a specialty that is generally reflective of the bodily system their symptoms impact most, the symptoms are typically first raised in primary care. Given the evidence that patients with MUS fight for physicians to recognize the legitimacy of their suffering and validity of their symptoms, (46) it is relevant to investigate the origins of this fight for legitimacy and the conditions that render this necessary, beginning with the initial clinical encounters about the symptoms. With the knowledge that primary care is typically the first line of care for MUS and that PCPs feel that they should be responsible for this care, as well as primary care's focus on the patient's overall health, it is necessary to investigate the nature of these challenges in the setting in which they originate.

Given the central role of communication in the clinical encounter, and the particular importance of communication with patients with MUS, (47) patient-centered communication is the key to reaching a shared understanding of illness and addressing it in a way that is responsive to the patient’s needs and beneficial to their health and functioning. In the next sections, the problem of MUS is contextualized first through an exploration of terminology and what it means for symptoms to be medically unexplained, followed by presentation of the conceptual difficulties that arise when symptoms appear to be medically unexplained, then the practical problems of addressing MUS in the primary care clinical encounter.

Part C: Terminological Ambiguity & Definition

There is substantial ambiguity surrounding the term “medically unexplained symptoms”. Most commonly, it is used to refer to symptoms that are unexplained medically and have primarily psychosocial causes. (28,48) O’Leary distinguishes between this narrow, prescriptive definition of the term and the more broad sense, to denote “*all symptoms for which patients seek biological care where providers have not found biological explanations* – including cases where biological causes are present but unrecognized, cases of benign self-limiting symptoms with biological origins, and cases where psychosocial distress is the primary causative factor.”(48) It is important to note that suggestion of psychosocial distress being causative of the symptoms is generally made after no organic cause has been found, with limited exploration of potential psychosocial causes, even when patients mention psychosocial concerns. (25,46,49,50) The physician’s perception of the disorder determines their approach to the symptoms, (28) many physicians have negative perceptions of patients with unexplained symptoms, and see them as not having legitimate medical issues, (51) so the assessment of the symptoms being psychological in nature without due exploration of the patient’s experience appears to be an act of dismissal and of undermining legitimacy. Further, use of the term MUS to signify that the symptoms are psychogenic in nature was in fact discouraged by the DSM-5. (52)

Various terms describe symptoms not satisfactorily explained by organic changes that imply psychogenic origins of symptoms. These include “Functional Somatic Syndrome”, which refers to patterns of persistent bodily symptoms for which adequate examination and investigation does not reveal a sufficiently explanatory structural or other pathology. (25) In the DSM-5, somatic symptom disorder combines undifferentiated somatoform disorder and somatization disorder, (52) and refers to any number of somatic complaints over several years, which began before the age of 30, are not fully explained by a general medical condition or substance use, and are not feigned. (53) The *International Classification of Diseases 11* has a code for bodily distress disorder, unspecified, and somatization disorder (54) as well as a number of functional somatic syndromes, such as fibromyalgia, chronic fatigue syndrome, and benign pain syndrome which are used preferentially according to medical specialty. (55,56)

The Cochrane Review on the topic of physical symptoms unexplained by disease uses the term Functional Somatic Symptoms in preference to MUS stating that it covers a more neutral and broad concept, (57) citing an editorial by Creed at al. (58) which claims that the term "MUS" has the advantage of expressing "that currently there is no 'organic cause' for the problem", leaving open its potential etiology, however arguing that the MUS terminology brings with it disadvantages. These include that it is a negative statement, withholding from the patient a positive explanation for their symptoms, and it is ambiguous, as it is unclear what counts as a medical explanation of a symptom, as well as fostering a dualism between organic problems that are "medically explained" and implying that those that are not are psychological in nature. Creed et al.'s criticisms of the term are reasonable, though I resist the conclusion that the term is inappropriate and inferior to "functional somatic disorder or syndrome". (58) The term "somatic" specifically refers to the body "as opposed to the mind" (59) and in medicine, somatic symptoms are understood to be physical symptoms that the patient is concerned about or excessively focused on, and attributes to nonpsychiatric disease. (60) Implied in the patient's stated attribution to nonpsychiatric disease, and the belief that patients are overly distressed by their symptoms, is that the patient is making an error, mistakenly believing the symptoms to be organic, and thus 'real', when they are not. "Functional somatic symptoms" or "functional somatic syndrome" are not immune to contributing to this mind-body dualism, and in fact, do so more explicitly through the use of the term "somatic", a direct reference to the body–and not the mind–that is absent in the term MUS.

In this project, the term "MUS" is employed broadly to refer to symptoms that cannot be attributed to an underlying explanatory pathology. This choice was made for a few reasons. All of the terms described above, including MUS, are necessarily inadequate in that they rely either on (a) the proof of a negative; of the absence of causal explanation for the symptoms and/or (b) on the identification of the symptoms as psychological in nature, as though a psychological etiology of an illness could be made entirely distinct from a somatic one. Additionally, (c) there is much stigma associated with these terms, many of which are poorly received by patients as they are perceived as dismissive, or for their implication that their symptoms are psychological in nature once they are deemed to not be adequately explained by organic changes. (61,62)

While MUS has been criticized for being an ambiguous and negative label that offers no insight into cause, (63) and terms that make reference to function have been found to be slightly preferred by patients, (63,64) in this project, the use of the term “MUS” is intended as an analytical concept to denote a heterogeneity of symptoms that are unexplainable within the reductionist biomedical model. The unexplained quality of the symptoms is reflective of the impossibility of reducing the complexity of the patient’s lived illness experience to an underlying pathological phenomenon. It does not mean that there is no explanation for this patient’s experience, rather that the explanation may be inaccessible or more complex than can be constructed within biomedical approaches to causation. Professing to understand and explain the symptoms through the attribution of a label that implies an explanation for the symptoms (such as one that attributes them to somatization or psychological distress) is a poor replacement for genuine communication about the patient’s illness, and a means by which their symptoms may be medicalized without evidence that this is beneficial. The arguments in support of these statements will be explored in detail in later chapters.

Throughout this thesis, MUS is used to denote symptoms for which no pathology that adequately explains the patient’s symptoms can be identified, understanding that the determination of etiology is not infallible nor objective, and that the conclusion that symptoms are medically unexplained may not be a permanent one. MUS does not, in this context, implicate a diagnosis nor the labelling of the symptoms. Rather, it is more neutral and agnostic than other commonly used terms, allowing space for explanation and discussion between patient and physician without the commitment to a specific symptom label. Further, it does not attempt to attribute the symptoms to a particular cause, particularly one that is psychiatric in nature, which is implied in many of the other commonly used terms, that I would argue perpetuate the reductionist approach of the biomedical model and consequently do not help in managing or understanding these symptoms. MUS indicates that the symptoms are medically unexplained–not that they are inexplicable. This leaves room for the reality that patients have diverse and often multiple explanations for their symptoms (65–67) and that there are several potential interrelated causes for symptoms that may not reveal themselves through biomedical investigation. Throughout this thesis, MUS is used in the broad sense to denote symptoms for which medical explanations are elusive, and MUS are distinguished from symptoms denoted psychogenic in nature, similar to the distinction elaborated by O'Leary. (48) When citing literature that employs other terminology, fidelity to that terminology is maintained.

The labeling of symptoms in the absence of explanatory pathology is essentially problematic, and this fundamental tension related to our inability to make sense of the symptoms medically converges with a number of other factors to make care for patients with MUS inadequate; poorly perceived by patients (68,69) and their physicians (41–43) alike. It is for the reasons outlined in this section–the false dualism of identifying symptoms as psychological when they are found to be unexplained, the requirement of proving a negative to diagnose MUS and the stigma associated with labels that imply psychological origins of the symptoms–that the broad sense of MUS is employed throughout this thesis. MUS is not used to refer to a specific diagnosis; it is employed with the belief that the *prima facie* problem of MUS is epistemic in nature, related to our incomplete knowledge of potential symptom causes (31) and ontological, related to the limitations of biomedical reductionism. The MUS terminology will reflect the uncertainty of the condition, remaining agnostic to causes. It is a label that is commonly used in the literature and does not presume a diagnosis, which is pertinent given that this project focuses on primary care and early presentations of MUS, and as such, it would be inappropriate to use a label that indicates a diagnosis of syndrome or a disorder. Thus, the term medically unexplained symptoms (MUS) is used throughout this text, without presuming that this is an appropriate or acceptable way of describing and explaining the symptoms to patients, as will be thoroughly explored in the remainder of this work.

Part D: The Conceptual Problem of MUS

Theoretical problems related to MUS involve at least four interrelated issues: i) A cause for the symptoms, or explanatory pathology cannot be identified after appropriate medical investigation, ii) It is unclear what comprises sufficient evidence in medicine for something to be considered a cause or explanation, iii) It cannot be proven that there is no cause for the symptoms, as this requires proof of a negative, and iv) Our understanding of MUS is distorted by a dualism where problems are seen either as real or psychological. (20) These four dilemmas and how they are related will be expanded upon in this section.

i. There is no evidence of a pathology that explains the symptoms after appropriate medical investigation

The label "unexplained" in this context indicates that the process of clinicopathological correlation, in which the patient's symptoms and clinical signs are used to guide the identification of an underlying pathology, fails to produce an explanation for the symptoms experienced by the patient. In this reductionist biomedical model, disease is what emerges at the end-product of a scientific, explanatory reduction of the evidence gathered clinically and through medical tests. (2) Generally, this reductive process is integrated in the clinical encounter with a more encompassing view of disease, the integral clinical conception, which is tied to the physician's clinical judgement. (2) The clinical encounter consists of the physician constructing medical meaning from the patient's experience of illness, using the methods of biomedicine–that is examination, imaging, and tests that allow for the identification of objectifiable pathologies–and their clinical judgement to translate the patient's illness experience into a tangible and actionable construct: disease. Within the clinical encounter, objectifying the experience of illness serves diagnostic and therapeutic purposes; most diagnoses relate to an objectifiable pathophysiological process. This allows for the bridging of the chasm between the lived experience of the patient and the scientific and biomedical knowledge of the physician.

The absence of explanatory pathology creates what Eriksen et al. call the epistemological problem of MUS, concerning our incomplete knowledge regarding the causes and contributing factors to the development of the symptoms and the absence of adequate psychological or organic pathology, which result in the symptoms remaining undiagnosed after medical examination. (31) This perspective sees MUS as symptomatic of underlying issues in medicine, reflective of the limits of reductionism. This is the say that the lack of medical explanation for the symptoms is not related to "some occult quality of the conditions themselves, but in the inadequacy of the framework applied to them." (12,20) The explanatory deficit lies in the reductive system that assumes simple causal connections between objectifiable disease and the individual illness experience, which fails to account for the complexity of embodied experiences and the intricacy of elements–physical processes, beliefs, behaviours, social context, family and personal history–that shape the experience of symptoms and the meaning-making process.

Thus, the *prima facie* problem of MUS pertains to our understanding of causation in medicine, that our failure to identify an explanatory pathology is due to a narrow understanding of causation. (31) Deary proposes a new ontology, wherein an explanatory model would not be organized hierarchically, but as a complex network of "physical processes, beliefs, behaviours, Benthamite fictions and cultural scaffolding interacting to shape the disease experience of an individual, none having causal priority over another." (20) This is in contrast to the biomedical model which assumes that there is a central, ontologically prior process that gives rise to symptoms, or even to the BPS model, which purports to provide a more holistic regard on the experience of illness, yet remains hierarchical and essentially mechanistic and "[…] excludes the centrality of the patient's experience in distinguishing *illness* from disease and neglects the distinction between pain as an essentially physical response and *suffering*, with its irreducibly experiential and cognitive elements."(17)

This more systemic, holistic perspective applies to symptoms that are medically explained as well as those unexplained. While medically explained symptoms may be attributed to an identifiable, objectifiable underlying pathological process, the particular way a given individual experiences the symptoms is unique, and shaped by their social context, beliefs about illness, cultural conceptions of disease, worries and concerns about what their symptoms might represent, among innumerable other intertwining elements, causes not appreciable within our biomedical ontology. For example, while low back pain (LBP) is frequently attributed to mechanistic causes, often underlying tissue damage, and mechanistic stresses such as posture and lifting, 90-99% of cases have no readily identifiable pathoanatomical driver to explain the pain experience. (18,70) While so-called abnormalities are exceedingly common on imaging of the spine in asymptomatic populations, (71) epidemiologically, these cannot be said to cause LBP. Etiologically, for an individual patient reporting LBP after a specific movement, both clinician and patient will likely consider the movement event to be causative, and in this case, it can be understood as the catalyst that instigated the person's pain. This cannot, though, be generalized to say that a particular movement causes back pain. The causality is unique to the context and the result of a network of interacting elements that contributed to the generation of pain[1].

When causal mechanisms are believed to be hidden, as is implied with MUS, this entails that the root cause must be found or discovered, which is often a frustrating, fruitless search for patients with MUS and their physicians alike. The search can lead to suspension of normal life as causes are investigated, and to potentially persistent symptoms, causing the patient to focus somatically and perform the sick role to become a 'credible patient', (44) exacerbating their illness (45) and decreasing self-efficacy[2] while waiting for a reason for their suffering that may never be identified. (20) This is not to say that research into MUS should be ceased, nor that investigating symptoms believed to be medically unexplainable is fruitless–rather, that causality must be understood more broadly and systemically. MUS, within this alternative ontology, requires a different understanding of causality. Seeing the causal mechanisms as currently hidden leads to the expectation that ultimately an explanation for the symptoms will be identified if enough information were collected and research conducted. (31) Rather, causality may be understood as a complex network of elements, life events, vulnerabilities and predispositions, unique to each individual and their lived context that shapes the symptoms they experience, regardless of whether biomedicine can identify a cause. With medically explained symptoms, the model holds, the central (pathological) causal mechanism simply shifts the weighting of factors, assuming more responsibility for the illness experience.

ii. It is unclear what comprises sufficient evidence in medicine for something to be considered a cause or explanation

With this discussion of a new ontology, the concept of causality in medicine must be clarified, to define what may be considered a medical explanation of a symptom. Russo and Williamson argue that health sciences make causal claims on the basis of physical evidence as

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[1] I would argue that a focus on the specific movement event as causative is misguided, as the overall context in which the movement occurred is likely more important, and focus on a specific movement as causative may be harmful: contributing to debilitating fear of movement (kinesiophobia), which is detrimental to the rehabilitation process and to resuming normal activities following a pain-provoking event.

[2] The confidence in one's capacity to control one's own behaviour and cope with prospective situations (72)

well as probabilistic dependencies. (73) They assert that to establish causal claims requires mutual support of mechanisms and dependencies, not monistic theories of either mechanism or probability, and that probabilistic evidence needs to be accounted for by an underlying mechanism before the causal claim can be established. (73) In a 2019 article, Williamson further supports the Russo-Williamson Thesis, explaining that "in order to establish a causal claim in medicine, one normally needs to establish both that the putative cause and putative effect are appropriately correlated and that there is some underlying mechanism that can account for this causation," arguing that this offers a better causal etiology than strict evidence-based medicine (EBM), which relies too heavily on randomized-controlled trials as the ultimate form of evidence, and fails to adequately consider validity for the target population. (74)

According to this model, the way we make sense of phenomena (symptoms, illnesses) in medicine relies on our ability to connect these to an underlying cause via a plausible mechanism. Thus, both an underlying abnormality that can be said to have caused the symptoms must be identified, and a mechanism by which this pathology results in the patient's experience must be understood. The putative effect would be the symptom, while the putative cause the underlying pathological abnormality for which there is a known mechanism that explains how it comes to cause the symptom in question. In the case of MUS, both the underlying cause and the mechanism that explains the cause are missing. While an individual may have identifiable abnormalities on imaging or other medical investigations, these cannot be reasonably said to be the cause of the symptoms they experience.

The construct of causality described here is consistent with the goals of EBM, "the conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients" (75) and with the non-hierarchical conception of symptoms as a complex network of interacting processes, as explained by Deary. (20) However, this falls short in practice in several important ways. First, this understanding of causality in medicine is generally restricted to linking biomedical or pathoanatomical causes with symptom effects, with a marked absence of rigorous criteria for mechanistically linking other contextual factors, including psychological and social phenomena, to symptoms. Second, these other contextual factors are infrequently discussed, as will be explored in detail in the context of MUS in primary care in next chapter's literature review. Third, while there is a growing body of literature exploring explanatory mechanisms for MUS, (76,77) these are theoretical, without a means to apply to the individual patient, especially given the limited exploration of the potential causal factors contributing to their symptoms. While this understanding of causality is, in theory, consistent with the conception of MUS put forth in this thesis and the ontology outlined in the previous section (a more encompassing understanding of causality and a more integrated use of evidence to make sense of illness), it is limited in its capacity to establish causality for symptoms outside of biomedical, pathoanatomical causal mechanisms. This reflects the aforementioned ontological and epistemological problems of MUS; our narrow, reductive understanding of causation in medicine results in our failure to identify an explanatory pathology, (31) and there is a marked failure to systematically investigate non-biomedical causes for symptoms.

With MUS, the issue is not that the symptoms are inherently inexplicable; rather, that causality is seen as strictly related to biomedical cause and effect, and absent if these cannot be identified, that understanding of the underlying mechanisms that could theoretically explain MUS is limited, and that patient's symptoms and lived context are not sufficiently explored in order to identify potential factors responsible for their symptoms.

This understanding of causality, if expanded to include the patient's lived context and their concerns regarding symptoms causes, would address the power differential in the clinical encounter, wherein the modern physician was given the belief, based on the capacity for clinicopathological correlation and their rich technical, biological expertise of the functioning of the human organism, that they had the ultimate authority and insight into the patient's illness. (14) Instead of the reductive causality to a disease process or the claim of inexplicability when no pathology is identified, this understanding would allow for a more encompassing and patient-centered approach to achieving a shared understanding of illness, in which the patient has the ultimate authority over their illness experience, bringing with them causal explanations and beliefs about the causes of their symptoms, as well as a (lived) understanding of their context and social situation, and the physician has the technical understanding of biomedicine and of evidence for risk factors to the development of MUS (such as health anxiety, history of childhood illness and family history of chronic illnesses, and concurrent general medical and psychiatric disorders (52,78,79)), and together, meaning-making regarding the symptoms, including appropriate diagnostic workup, can be undertaken to reach a shared understanding of illness.

iii. It cannot be proven that there is no cause for the symptoms, as this requires proving a negative

If the term medically unexplained is taken to mean that there is no explanation for the symptoms in question, this would require that every existing explanation for the symptoms had been thoroughly considered, and every medical investigation performed, a virtual impossibility. It is for this reason that MUS is defined in this thesis as the inability to identify a pathology to adequately explain the patient's symptoms, not based on the absence of pathology nor lack of cause. The 'unexplained' quality is reflective of medicine's inability to explain the symptoms within our current ontology that is largely restricted to pathoanatomical causality.

When no explanatory pathology can be identified to explain the patient's symptoms, such as when tests do not reveal an abnormality, the physician's sources of information fail and they cannot rely on their professional authority alone to make sense of the patient's experience. (46) In fact, diagnostic tests are often used as a means of reassurance when there is a low pre-test probability of serious disease, a practice which, in a systematic review and meta-analysis, has been found to not reassure patients, nor decrease illness worry or symptom persistence. (38) The common use of this practice speaks to a false implicitly held belief by physicians that the absence of evidence of pathology on a diagnostic test establishes that there is no cause for the symptoms, a negative that cannot be proven. Use of reassurance or normalization of symptoms after normal diagnostic tests is common practice and generally poorly received by patients. (42,57,80) This is one example of the conceptual problem with MUS–in this case the faulty assumption that a negative diagnostic test reflects that there is no cause for the MUS–translating into practical challenges in the care for patients with MUS. This can also be understood as the fallacy of misplaced concreteness, the dismissing of illness experiences as "superficial, spurious and 'subjective'" and the assumption that only scientific investigation can access the objective truth of things. (81) The fallacious belief that negative tests are evidence of no cause for the symptoms is more often implied than explicit, it is the assumption that the symptoms are unexplainable, rather than unexplained. It relies on the physician's authority as gatekeeper of medical information and of diagnosis, and lack of evidence for a causal mechanism is often used as a means of dismissing patients with MUS.

iv. Our understanding of MUS is distorted by a dualism between real and psychological

In addition to ineffective and dismissive reassurance when no cause for the symptoms is found, psychological attribution for MUS is often made without due process of exploring and investigating psychosocial and contextual factors that may be contributing to the patient's symptoms. Often, the lack of identifiable organic pathology is taken as proof of lack of cause, and this leads to their attribution to psychological causes, labelling the symptoms with nomenclature such as "psychosomatic", "psychogenic" and "somatization". With these terms, mind-body dualism is implied, pathophysiology is oversimplified, and it is suggested that the patient is transforming their mental conflict into physical problems. (82) This leap–from the lack of identifiable explanatory pathology for the symptoms, to the suggestion of a psychiatric cause–is often made without systematically exploring psychosocial causes, but rather pursuing unlikely organic pathologies through additional testing, (25) a fortuitous attempt to prove a negative.

While designating symptoms as psychosocial in nature appears to be progress over the strict reductionism of the biomedical model, adopting a BPS model in which illnesses are understood as the product of complex interactions between the realms of biological, psychological, and social worlds, it is nonetheless based on the Cartesian notion of physical and psychological duality. (17) This reflects the shortcomings of the BPS model, which purports that the biological, psychological, and social can be teased out from one another, that they can be systematically separated within an individual to identify where the cause of the symptoms lies. This model, often applied in a fragmented manner, (18) contributes to the perpetuation of reductionist and dualistic beliefs about the nature of symptoms. Within a framework that artificially separates the body and the mind, despite patients experiencing symptoms as a unified whole, (83) symptoms that are medically unexplained will remain as such.

The symptoms are unexplained inasmuch as they cannot be reduced to being the result of a pathological process, and in labelling the symptoms as psychological, the physician implies that the patient is making an epistemic error, "misinterpreting and misrepresenting psychological distress as physical symptoms." (20) This belief–that patients with MUS have difficulty appropriately processing their emotions and have dysfunctional perceptions of their bodily experiences–is widespread, not entirely accurate, insufficiently supported by evidence to merit its inclusion in the UpToDate review of somatic symptom disorder (78) especially considering its contribution to existing biases against patients with MUS. Further, psychosocial causes of symptoms cannot truly be teased out from biological ones; the model offers no methodology to identify the relevant data, nor does it indicate which level of analysis to prioritize to determine which factor is ultimately responsible. (84)

The leap from lack of organic explanation for the symptoms to assumed psychological causality additionally enforces the narrative that psychological illness is not real or legitimate. It implies that if there is no identifiable organic pathology that is deemed causative, then, in the absence of cause, the symptoms can be attributed to psychological distress. This conclusion is often drawn with limited exploration of psychosocial factors in the clinical assessment. (25,46,49,50) Deary outlines the historical development of Cartesian dualism and how this contributes to an understanding of a hierarchical connection between root physical causes and mental epiphenomena, which is fundamentally challenged by MUS, in which a root pathoanatomical cause cannot be identified. The concept of hysteria attempts to "patch up the inadequacy of this model," by pretending that the mental can influence itself within a model that sees the mental as part of the physical. (20) Hysteria, as defined by Freud, is the conversion of distress into physical dysfunction. (85) The circularity of attributing physical symptoms without explanation to hysteria becomes evident.

Hysteria, a phenomenon experienced virtually exclusively by women (86) is still used as a diagnosis under different names. Notably, the term "somatoform disorder" was used to rebrand the concept of hysteria, packaging it so that patients would be less inclined to resent and resist the diagnosis. (48,86,87) While unexplained symptoms are diagnosed more frequently in women (68)–patients with persistent MUS have been found to be more often female, public health insured, older, widowed, non-Western, and to have a lower education level, (69) and functional syndromes are more prevalent in women; fibromyalgia has a five times greater incidence among women than men, (88) and Irritable Bowel Syndrome is diagnosed at a far higher rate in women than men, regardless of the diagnostic criteria employed (89)–this does not mean that psychogenic symptoms predominantly affect women. The scientific evidence for this claim of a genuine difference between women and men with regards to these symptoms is lacking. (48) The importance of this gender difference in unexplained symptoms and those deemed to be psychogenic in nature, as well as the labelling of unexplained symptoms as psychological will be further explored in the third chapter. Female sex, fewer years of education, lower socioeconomic status (78) as well as non-Western origin (69) are said to be risk factors for MUS, but it is worthwhile to consider that these may in fact be risk factors for the physician to more readily dismiss symptoms as non-medical, illegitimate, and psychological.

In addition to the impossibility of proving a negative in order to conclude that symptoms are medically unexplained, and the identification of symptoms as psychological in nature when the necessary investigations do not produce an explanation, terms that imply a psychological origin of symptoms have been found to offend patients, (64) implying that symptoms are imaginary or made up. (90) Patients perceive psychological attributions for their symptoms, particularly in the absence of exploration of psychosocial factors, as invalidating their experience, though evidence suggest that when psychosocial factors are explored, psychological and social explanations are acceptable to patients. (49,91) While psychological labelling of symptoms may be stigmatizing and invalidating–reinforcing a dichotomy between 'real' symptoms and 'fake', psychological ones–appropriate exploration of symptoms and subsequent determination that psychosocial factors may be significantly causative can be constructive. It is the suggestion that symptoms are not real often implied with the way the psychosomatic (and related) labels are used that is invalidating, dismissive and stigmatizing. The implied dichotomy–that symptoms are either legitimate and medical, supported by objective data, or illegitimate and psychological–that reinforces ideas about patients with MUS performing their suffering for attention and contributes to narratives undermining the legitimacy of psychiatric illness.

Part E: The Practical Problem of MUS in the Clinical Encounter

In this section, I elaborate upon the ways the theoretical challenges explored in Part D contribute to the dysfunctional clinical encounters and often discordant relationships between patient and physician. We hear a great deal about how these patients frustrate physicians and are considered difficult patients, (37,92–95) how patients with MUS are demanding (33,96,97) and cause ‘heartsink’. (98,99) I explore how these perceptions of patients with MUS demonstrate existing biases against patients, which, alongside theoretical challenges, contribute to substantial difficulty and uncertainty in caring for patients with MUS.

As patients seek medical care in large part to understand their symptoms and determine what they represent, (1) being informed that there is no clear cause for their symptoms is understandably a frustrating and confusing experience. The absence of identifiable medical cause for symptoms, often conveyed to patients in a way that they perceive as blaming and dismissive, appears to undermine their authority over their illness with the physician’s authority over the biomedical realm.

To ensure that their illness experience is attended to, patients resort to strategies to engage with their physician. When interactions between patients and physicians regarding MUS are analyzed, it is found that patients may portray the importance and severity of their symptoms through extreme case formulations (46) and may use graphic and emotional language, providing complex patterns of symptoms. (37) Patients’ presentations of their symptoms depend on the attitude of their PCPs concerning psychosocial aspects. (100) Methods employed by patients can be seen as calls for attentiveness to their suffering, demands for empathy and understanding that they do not feel they are receiving. Patients may in fact begin to focus more somatically as a result of these efforts to have their experience legitimized; exacerbating their symptoms and causing them to perform the sick role to become a ‘credible patient’, (44) and these efforts may backfire. Attempts to engage with their physician may prompt further skepticism and negative feelings from the physician, and renewed patient efforts to establish their credibility (101), as well as being met with resistance or disengagement, even rejection by their PCP. (34,102)

Physician beliefs about patients with MUS shape the course of the clinical encounter, both before the determination that symptoms are medically unexplained and afterwards. PCPs have been found to struggle at the conceptual and relational level, related to their biomedical concepts of disease and how these oppose the personal illness experience of patients and patient’s own explanatory models. (28) Here, we see the patient’s efforts to engage with the physician, and the physician’s reactions to cues or statements made by the patient. Patients may escalate the encounter when they feel their suffering is not adequately being attended to, and physicians may in turn detach themselves or become distant, unresponsive to the patient's needs, as they become increasingly frustrated or perceive that the patient is making demands for inappropriate medical care or even seeking care in the inappropriate setting if they feel their symptoms are not medical in nature once no explanatory pathology is identified.

Physicians have various methods of controlling the trajectory of the clinical encounter with patients with MUS to ensure that it does not go "off track", using restricted question-answer sequences, (46) or colluding with patients' suggested explanations to decrease resistance in the encounter. (103) Without the authority provided by conclusive results of biomedical investigations, and without an understanding of the patient's illness experience, the clinical encounter reflects this knowledge deficit, and care for patients with MUS does not address their need for explanation nor attend to their concerns.

In response to patients' presentations of MUS, physicians may provide psychological explanations for symptoms, despite theories of psychogenic causation and somatic amplification not sufficiently explaining MUS, and the evidence that these explanations are often communicated poorly, do not address patients' concerns and may lead them to reject treatment. (104) Often, explanations offered for MUS fail to engage with patients' beliefs about their symptoms and are perceived as dismissive, reflecting inadequate exploration of concerns in the clinical encounter, reliance on biomedical expertise and objective findings that fail to provide.

Patients have been found to indicate what they want from their physicians, including discussion of psychosocial problems as a means of indicating need for emotional support, and suggestion of physical explanations as an indication of a desire for explanations and reassurance. (32) Providing reassurance is one of the most common management strategies for MUS, (105) though reassurance often fails, (106,107) which may in part be related to modes of reassurance that do not engage with patients' concerns. Patients bring with them to the clinical encounter multiple explanations for their symptoms, (65–67) borrowing from medical concepts in their accounts of their symptoms. (97) When physicians provided explanations that questioned the legitimacy and veracity of symptoms, patients have doubted their authority and perceived them as incompetent. (97) Appropriately communicating with patients about symptoms that are medically unexplained poses a challenge to the physician, disrupts the dynamic of a typical clinical encounter and the patient-physician relationship, (51) and frustrates physicians, (41) not to mention that patients are indelibly harmed when they are rejected and their experience is denied, and particularly when they remain in diagnostic limbo, awaiting an explanation, their life suspended in anticipation of a cause for their suffering that may never be identified, (20) which may contribute to the development of chronic disablement. (108) The belief that an underlying cause must be identified for the symptoms to be legitimate is harmful to patients who are provided with spurious causes as well as those who are dismissed outright when no cause is identified. The narrow focus on the organic explanation for what is a complex problem may reinforce patients' concerns about physical disease. Indeed, many patients continue to undergo numerous fruitless investigations and attempts at treatment, (108) contributing to an iatrogenic process and unproductive and harmful focus on the symptoms.

Clinical consultations surrounding MUS are fraught due to the inability of the physician to objectify the patient's experience, which they rely on to maintain their authority in the clinical encounter. Additionally, beliefs about psychological causation, and about the significance of negative investigations shape the physician's response to the patient's expressed symptoms and needs. Existing biases and firmly held notions about patients with MUS being difficult (93,109,110) or that they are mistakenly interpreting psychological distress as physical symptoms, (20) displays underlying beliefs that patients are not reliable and cannot be trusted to experience their lived body correctly and to express this honestly. It says, essentially, that the patient is incorrect in the way they experience their illness, that their suffering is not valid, and that they do not have the authority to make sense of their own bodily experience.

Conclusion

Inability to provide a medical explanation for the patient's symptoms, which reflects an ontology that prioritizes biomedical explanations for symptoms over all else, as well as implicit beliefs about a division between "real illness" and psychological illness are translated into clinical encounters in which the physician does not have recourse to their usual approaches to treating patients. Given the prevalence of MUS, this reflects a large, ontological issue with biomedical care that is not adequately addressed with a transition to a biopsychosocial model. The impossibility of proving a negative–of establishing that there is absolutely no cause for the symptoms–seems to be an additional challenge to clinicians who might want to dismiss the patient's symptoms as being illegitimate when no cause is found, as though the unexplained nature of the symptoms reflects a true lack of explanation. Questions about what comprises sufficient evidence to determine causation (or lack of causation) remain, which is highlighted by the use of additional testing despite low pretest probability as a means of ruling out any potential causes, an impossibility. Existing biases, combined with legitimate theoretical problems and discordant means of communicating, concomitantly create clinical encounters that are harmful to patients with MUS and frustrating to physicians responsible for their care.

In the following chapter, these epistemic and empirical problems with MUS are examined closely through the lens of communication. A critical interpretive literature review brings forward patient narratives and beliefs about their symptoms, how they ask for medical care, and how physicians explain the symptoms to patients. There are notable challenges for communicating about symptoms that are medically unexplained, and evidence that many of the methods employed are ineffective, poorly received by patients, and often harmful. This review of communication regarding MUS will inform the discussion of the ethical issues in the care of patients with MUS and how these are manifested in communication, as well as the development of evidence-based approaches to caring for patients with MUS in the primary care setting, where much of this care occurs. There is a dire need to improve care for patients with MUS. Communication, which is central to the clinical encounter and particularly challenging and important with patients with MUS, (47) may be the key to addressing what appears to be a fundamental and intractable problem in (largely) biomedical practice. The aforementioned epistemic and ontological problems of MUS can be addressed through a broader understanding of symptom causation, and through a prioritization of the patient's experience of illness and the patient-physician relationship, which may be attained through the methods of patient-centered medicine. (19)

Chapter 2: A Critical Interpretive Literature Review of Beliefs, Expectations and Communication Regarding Medically Unexplained Symptoms in Primary Care

Background

Medically Unexplained Symptoms (MUS)–somatic complaints or physical symptoms that persist for a number of weeks, cannot be attributed to psychoactive drug use, and cannot be explained satisfactorily by organic changes (23–25)–can be a challenge to address appropriately in the clinical encounter. Given the impossibility of establishing causation of MUS within the current biomedical ontology, it can be difficult for the clinician to satisfy the patient's need for an explanation. Additionally, the negative perceptions PCPs have of patients with MUS, the challenges they face in caring for them, the pervasive belief that that which is medically unexplained is attributable to psychological causes, and incongruence within the patient-physician relationship contribute to the challenges faced by the patient and the PCP.

Communication is fundamental to the patient-physician relationship, and effective patient-physician communication is positively associated with a number of beneficial patient outcomes, including improved patient understanding and adherence to therapy, (111) and is particularly important for patients with MUS. (47) Communication is of particular relevance in the primary care setting, in which patients typically have their first medical encounter regarding their symptoms and may be first informed that the symptoms are medically unexplained. Encounters in primary care can set the tone for how patients learn to interact with clinicians in order to be taken seriously. There are several barriers to effective patient-physician communication in the MUS consultation; including physicians' difficulty in communicating with the patient about their symptoms, given the lack of diagnostic findings that would explain the patient's illness and their feelings of frustration with patients with MUS that may compromise their ability to communicate effectively. Reaching a shared understanding of the patient's illness experience is instrumental to a way forward in caring for patients with MUS in its protective effect against persistent search for meaning for symptoms and dismissal from healthcare providers, which may lead to suspension of normal life as causes are investigated, and decreased self-efficacy as one waits for a reason for their suffering that may never be identified. (20) It will be useful to explore the diversity of patient explanations for their symptoms, alongside the care and communication-related expectations from their PCPs and the strategies PCPs use to communicate with patients about their symptoms. Elucidating patients' approaches to expressing their symptoms and their needs for care will guide the analysis of these barriers and how they can be addressed for more responsive and effective care for patients with MUS.

Thus, this chapter investigates communication between adult patients in primary care and their PCPs regarding MUS. Three primary questions are investigated:

1. What are the beliefs of patients with MUS regarding the nature of their symptoms?
2. How do patients express their beliefs and desires for care in primary care?
3. How do PCPs communicate with patients and respond to their requests and expressed needs?

Employing a critical interpretive literature review, this investigation focuses on the explanations, reassurance and normalization of symptoms offered by PCPs, and how these are perceived by patients. This allows for further critical discussion of how PCPs ought to communicate with patients regarding MUS in a way that is acceptable to patients, truthful, ethical, and health-promoting.

Methods

Protocol and registration: The protocol is summarized below. It was not registered.

Study design: A critical interpretive literature review (112) is conducted to identify practices and analyze communication regarding MUS in primary care. This approach allows for a broad perspective on the subject through a thorough literature search. Without conducting a systematic search that assembles every article relevant to the research question, the studies identified comprise a body of knowledge that enables a specific research question to be answered, thus extending this body of knowledge through a synthesis of the evidence. (112) Employing this approach, a comprehensive literature search was conducted, and articles were then rigorously screened to identify those that explicitly provided insight into the three research questions. This approach is particularly well-suited to bioethical inquiry, where attempting to capture all papers on a topic may not be necessary nor appropriate, (113) given the nature of arguments on ethical justifiability, which do not rely on the entirety of the evidence on a given subject in the same way that empirical biomedical research questions often do. (112) The critical interpretive review–which analyzes the literature as a whole, and individual findings within that literature, to answer specific research questions while assessing quality without employing rigid quality assessment criteria in order to capture key ideas in the literature and put forward an argument–is well-suited to research of this nature. Concerns about redundancy are minimized by the nature of the critical interpretive review (as compared to a review employing quantitative methods to aggregate the literature).

Eligibility criteria: This literature review includes primary investigations responsive to the three questions outlined above. This includes qualitative research, cross-sectional studies, cohort studies, case series/case reports, prospective/longitudinal/follow-up studies, quantitative research, dissertations/theses, books/book chapters, editorials, letters and comments. Systematic reviews and meta-analyses were included during abstract screening, and during full-text screening, reference lists of these were reviewed to identify relevant studies for inclusion in this review. Some review papers were included if they included novel research (such as Kirmayer & Young (1998) (79)) or if they directly responded to the research questions. No restrictions of publication year, publication status or language to ensure a comprehensive search. During full-text screening, full texts unavailable or those unavailable in English or French were eliminated.

Information sources: The following electronic databases: Ovid (Including Embase (1996 to 2020) Ovid MEDLINE (R) ALL (1946 to April 15, 2020) and PsycInfo (1967 to April Week 2 2020) and the Cochrane Library were searched. Additionally, information was extracted by hand by reviewing the reference list of included studies. Citation notices were created for key authors identified. The search strategy was updated and improved throughout the literature review process, based on the yield of initial searches and comparisons with previously identified important pieces of literature. Additional derivatives and relevant keywords were added, and some which did not yield relevant results were improved or removed. Given the heterogeneity of vocabulary to denote medically unexplained symptoms and that literature on this topic is dispersed across multiple subjects, the following ancillary search procedures were employed: reference list searching, similar articles feature, co-cited article searching, forward citation searching, and hand searching. Hand searching was used to review BMC Family Practice, Psychosomatic

Medicine, Journal of Psychosomatic Research, The British Journal of General Practice, Psychosomatics and BMC Medical Ethics.

Search strategy: A literature search identified the publications reporting the communication surrounding MUS in primary care and the perception of this communication by patients. MUS is a heterogeneously defined topic with variable terminology, and as such, diverse search terms were employed to capture the scope of relevant citations. These search terms were combined into a single search, which was combined with searches on 1. Communication 2. Patient expectations and 3. Physician responsibility and duty of care. Using OVID, this search was conducted in three databases, Ovid MEDLINE, EMBASE, and PsycINFO. The Cochrane Library of Systematic Reviews was subsequently manually searched. The third search term was included to draw out literature on ethical questions related to MUS, but this data was not included in the critical interpretive review. The full search strategy is included in Table 1.

Table 1: Search terms and approach

#	Searches
1	(Explanation* or Communication or Reassurance or Dialogue or Attitude* or Normali#ation or management or response*).mp. [mp=ti, ab, hw, tn, ot, dm, mf, dv, kw, fx, dq, nm, kf, ox, px, rx, ui, sy, tc, id, tm, mh]
2	(Patient and (Expectation* or Desire* or Wishe* or narrative* or Demands or dialogue or approach or interpretation or diagnostic interaction or strateg*)).mp. [mp=ti, ab, hw, tn, ot, dm, mf, dv, kw, fx, dq, nm, kf, ox, px, rx, ui, sy, tc, id, tm, mh]
3	((Physician or Doctor) and (Responsibilit* or Dut* or Care or Ethic* or Bioethic* or Medical Ethic* or biomedical ethic*)).mp. [mp=ti, ab, hw, tn, ot, dm, mf, dv, kw, fx, dq, nm, kf, ox, px, rx, ui, sy, tc, id, tm, mh]
4	((Medically adj2 Unexplained Symptom*) or Unexplained symptom* or Medically Unexplained Illness* or Somatic Symptom Disorder* or Somati#ation or Bodily Distress Syndrome* or Somatoform disorder* or somati#ation disorder* or Contested Illness* or Functional Symptom* or Non-specific condition* or non-specific symptom* or unexplained physical symptom* or symptom* unexplained).m_titl.
5	1 and 4
6	2 and 4
7	3 and 4
8	5 or 6 or 7
9	remove duplicates from 8

Study selection: The search yielded 1621 unique results, which were exported to Microsoft Excel with abstracts. To ensure only relevant articles were included, studies that did not fit my definition of MUS, those that did not respond to the above three guiding research questions, and those that discussed treatment modalities for MUS were excluded. Studies focusing on the etiology or investigating causes for MUS were excluded. During abstract review, no limits were applied to publication year, status, language or patient population to maximize the results. Following abstract review, 114 articles were identified as responding to (at least) one of the three research questions. During full-text review, it was determined whether articles met the eligibility criteria AND if they responded to at least one of the three research questions.

Data charting: Data was extracted through close reading of these articles by the study author, and through input into thematic trees and summary tables. No calibrated forms were used. Data charting was done independently and iteratively, and sources were re-screened over one week after each initial screening to identify any missed data.

Data items: The variables for which data was sought were article characteristics (country, type of study), conditions being investigated (e.g. MUS, somatoform disorders), population demographic characteristics, assessment tools (e.g. illness perception questionnaire) and results (patient beliefs and expectations of physicians, methods of communication regarding MUS).

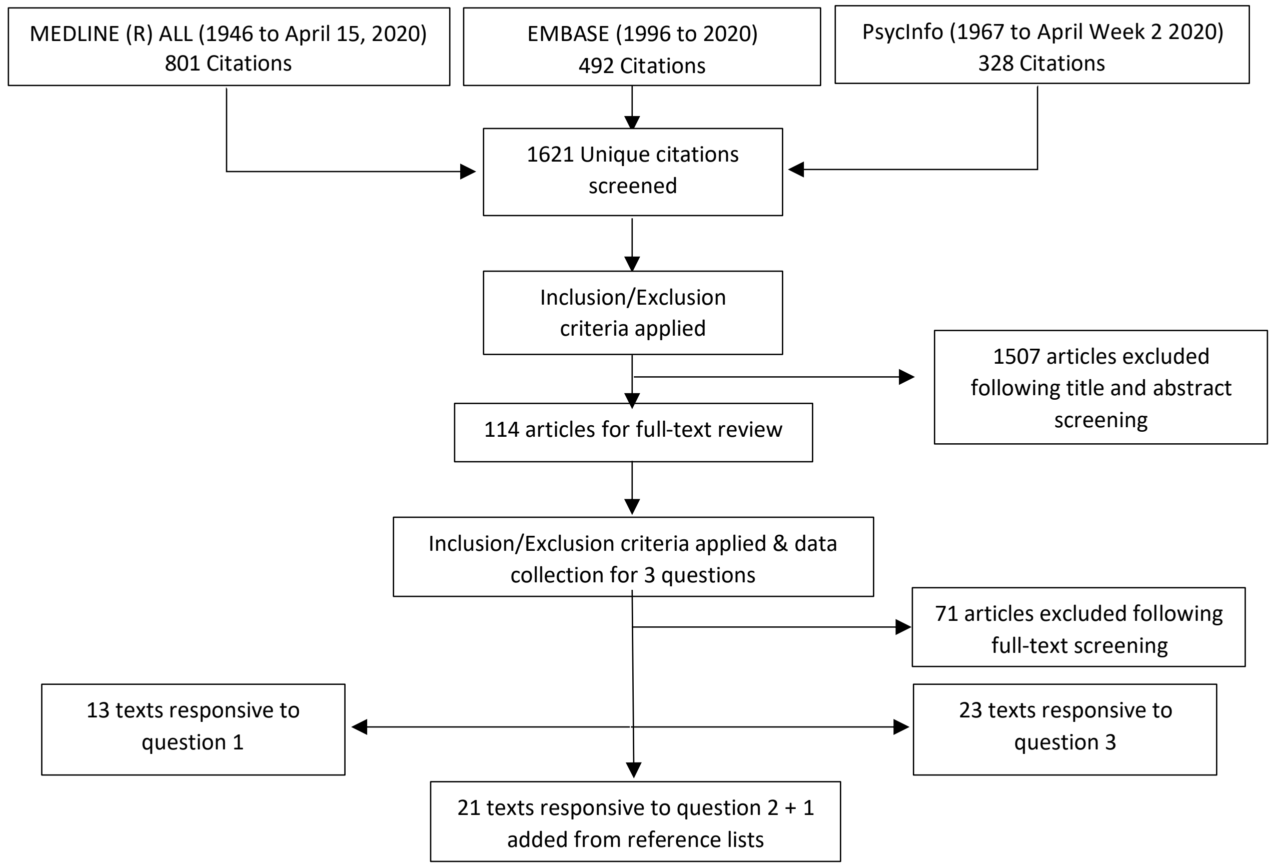
Critical appraisal of individual sources of evidence: During full-text screening, quality of the individual texts was subjectively determined based on potential for biases including (notably) social desirability biases in responses by patients and physicians, selection biases, and recall bias. A systematic approach to critically appraising individual sources of evidence is outside of the purview of a critical interpretive review, which aims to answer a research question and capture key ideas relevant to a research, analyzing the literature as a whole and generating theory, without excluding papers based on rigid quality assessment criteria. (112)

Synthesis of results: Employing the strategies of the critical interpretive review methodology, the studies were grouped by general themes (112) determined based on the three primary research questions identified: 1. What are the beliefs of patients with MUS regarding the nature of their symptoms? 2. How do patients express their beliefs and desires for care in primary care? 3. How do PCPs communicate with patients and respond to their requests and expressed needs? The data was summarized and critically appraised. When a systematic review or other review or commentary paper was included in this review, the reference list was screened to identify relevant studies for inclusion, and results and discussion from the systematic review were used to inform commentary on the articles in question. Studies missed by the search and added to the review in question were noted.

Search Results

Selection of sources of evidence: The primary search identified 1621 articles after deduplication. The titles and abstracts were screened for relevance, assessed by their responsiveness to the previously identified research questions, and whether they corresponded to the correct clinical population (adults in primary care, general practice, family medicine). Following abstract screening, 114 articles remained. During the subsequent full-text screening, reference lists were manually searched, and a total of one article was added to the review. Prominent authors' works were searched, yielding no additional results. The Cochrane database was manually searched, yielding one relevant review article. The final search was conducted 15 April 2020. The PRISMA diagram illustrating this process is included in Figure 1.

Figure 1: PRISMA diagram illustrating the process of identifying studies for inclusion



Question 1:

What are the beliefs of patients with medically unexplained symptoms (MUS) about the nature of their symptoms, and how are these concordant or discordant with the explanations provided by their primary care physician for symptoms deemed to be medically unexplained? Beliefs of patients regarding their symptoms include explanatory models, causal attributions of their illness, illness perceptions and concerns regarding the meaning of their symptoms.

Thirteen articles were identified as responding to this first question; nine specifically considered patients with the label 'medically unexplained symptoms', two articles considered somatisation (one of which was a literature review) and another two somatoform disorders. All studies considered patients in primary care or family medicine units, though one was conducted in a general internal medicine clinic that acted as first line care for refugees, (114) and another in a Veterans Affairs tertiary care clinic that focused on MUS. (115) The tertiary care clinic provided primary care to these veterans, hence its inclusion in the review. The data collected from these sources in summarized in Table 2.

Table 2: Summary of findings in articles responding to Question 1:

Authors	**Condition, n**	**Methods**	**Results – Explanatory models**
Kirmayer & Young (1998). (79)	Medically unexplained somatic symptoms or multiple somatic complaints, n=120	Ethnographic community study, interviews to elicit illness narratives, then ask for formal explanatory models.	Three idioms of distress, widely used across cultures: - Stress, disturbances to the bodily/emotional equilibrium of health - Pollution, the environment as a constellation of meanings - Traumatic events
Peters, S., *et al.* (1998). (97)	MUS patients with a 12-month history of unexplained symptoms, n=68	Qualitative interviews, inductive thematic analysis grounded in data	Complex understanding of symptoms relating bodily experiences to social and emotional phenomena. Generally, explanations were fluid and incomplete or unsatisfactory to patients. Four themes emerged: - Disease entity - Social influences - Internal imbalance - Nervous and psychological mechanisms
Rief *et al.* (2004). (66)	Unexplained physical symptoms, n=233, of which 193 met criteria for somatoform disorders	Illness Perception Questionnaire (IPQ) to assess cognitive representations of illness. Quantitative data, factor analysis	Most patients reported multiple illness attributions. More symptoms were associated with more attributions, including: - Vulnerability - Organic causes - Psychological causes
Ring, A., *et al.* (2005). (50)	Patients with MUS as identified by their GPs, n=420	Audiotaped consultations Liverpool Clinical Interaction Analysis Scheme (LCIAS) to quantify types of verbal communication. Quantitative.	397 patients indicated psychosocial problems; disclosing them directly or suggesting psychosocial explanations. 355 offered any explanation: firm or tentative attribution of problems to physical disease, other physical or psychosocial factors, normal influences not requiring treatment, other causes: - 172/397 offered firm or tentative attribution of somatic symptoms to psychological, social or lifestyle factors. - 4/397 indicated that psychiatric disease might contribute
Junod Perron, N. & Hudelson, P. (2006). (114)	Somatisation, refugees and asylum seekers n=26	Semi-structured interviews. Qualitative analysis of key themes in narratives.	19/26 patients identified pre-migration experiences (especially traumatic events) as underlying cause of illness. Suffering was attributed to physical and social causes. Associations between past trauma and current symptoms did not preclude a belief in a physical cause of suffering.

Sumathipala, A. *et al.* (2008). (116)	MUS, 5+ symptoms of any duration n=68	Short Explanatory Model Interview (SEMI) with 1 open-ended question: 'What do you call these problems (symptoms)?' Qualitative & quantitative analysis.	Identity of symptoms: 59% of participants could not offer any diagnosis or label. 21% provided a physical diagnosis, 19% provided non-specific terms indicating a physical aetiology Cause of symptoms: 56% did not offer a specific cause, 26% mentioned a cause relating to the internal world, 15% to the social world, and 3% to the natural and super-natural worlds.
Risør, M. B. (2009). (117)	MUS n=9	Repeated, semi-structured, qualitative interviews. Thematic content analysis on a pragmatic and phenomenological basis	Patients employed four explanatory idioms: - The symptomatic idiom: suffering assumed to be caused by a physical disorder, about trying to find a cure for symptoms. Behind the use of this idiom is a bodily experience. - The personal idiom: expresses one's liability to illness as certain personal characteristics, aspects of the psyche. - The social idiom: illness caused by environmental factors, work situations and general social life constraints. Stress is the decisive element that leads to an outbreak of symptoms. - The moral idiom: An encompassing view, considering the essence of one's life, trying to find meaning and coherence.
Hiller, W. *et al.* (2010). (67)	Somatoform Disorders (SFD) (n=79) compared to patients with chronic pain (n=187)	Causal Attributions Interview (CAI) Semi-structured interviews, quantitative comparison of illness attributions assessed: i. spontaneously reported, ii. Selection from a list, iii. Weighing causes, iv. Origin of attribution, v. stability of attribution over time.	Attributed symptoms to mental or emotional problems (46.9%), somatic diseases (41.1%), physical overloading/ exhaustion (29.1%), daily hastiness and time pressure (21.4%), unhealthy lifestyle (18.6%), suppressed inner conflicts (17.6%), negative life events (14.8%), family or interpersonal problems (13.3%) 24% of symptoms attributed to environmental causes (EC), 65.4% to somatic causes (SC), 68.9% to psychological/stress-related causes (PSC). 25.6% attributed symptoms to both PSC & SC. 11.4% to both PSC & EC. 9.8% to a combination of all three. When analyzed across all symptoms on a patient basis, the overlap between PSC, EC and SC accounted for 40.5% of attributions. 36.7% to both SC & PSC.
Nunes, J. & Ventura, T. (2013). (118)	Medically Unexplained Physical Symptoms (MUPS), 6 months following diagnosis. n=15	Qualitative analysis of interviews, semi-directive method, some open questions, some scripted.	Past experiences contribute to development of ideas about causes of symptoms, explanations change over time. Most patients identify psychosocial causes. Those with biophysical explanations for their symptoms before the consultation changed their explanation afterwards and explicitly described this change. Personal experience or family history of symptoms associated with psychosocial situations was associated with attribution of current symptoms to psychosocial causes.
Lidén, E., Björk-Brämberg, E. & Svensson, S. (2015). (119)	MUS n=10	Phenomenological-hermeneutic method, narrative interviews. Qualitative study.	Various explanatory frameworks used, including: - Poor genetic immune defence - Personality and ability to handle pressure - Trauma, social issues, relationships, difficulties involving lack of structure and control in private life and/or work. - Overloaded work situation - Unemployment - Tense body, distinguishing between illness & person
Sowińska, A. & Czachowski, S. (2018). (65)	Diagnosis of distinctive somatoform disorders, >2 years of symptoms. n=20	Qualitative content analysis of filmed semi-structured interviews.	Most patients drew on various explanatory frameworks while describing their symptoms. Most expressed with uncertainty. - Personal weakness, internal factors - External, social factors - Somatic explanations
Dwamena, F. C., *et al.* (2019). (120)	MUS, n=19	Transcripts of interviews, iterative consensus building analysis. Qualitative study, grounded theory.	Expressed or inferred concern about serious undiagnosed disease. Most patients expressed or inferred awareness of the relationship between personal psychological stress and physical symptoms.
Phillips, L. A. & McAndrew, L. M. (2019). (115)	MUS in veterans, n=243	Closed questions about perceptions about the nature and/or identity and causes of symptoms. Qualitative. Likert scale	Belief that symptoms are caused by: - Internal, biological factors: 2.73/5 - Environmental or external agents or events: 4.12/5 - Mental factors/psychological causes: 2.45/5

Synthesis of results

Most studies included were qualitative in nature, with one that used both qualitative and quantitative analysis of interviews (116) and three of the thirteen that quantitatively analyzed the data. (50,66,67) Given the heterogeneity of the participants, methods of eliciting illness attributions, and data analysis, the results were compared qualitatively, and themes were drawn out iteratively throughout the literature review process.

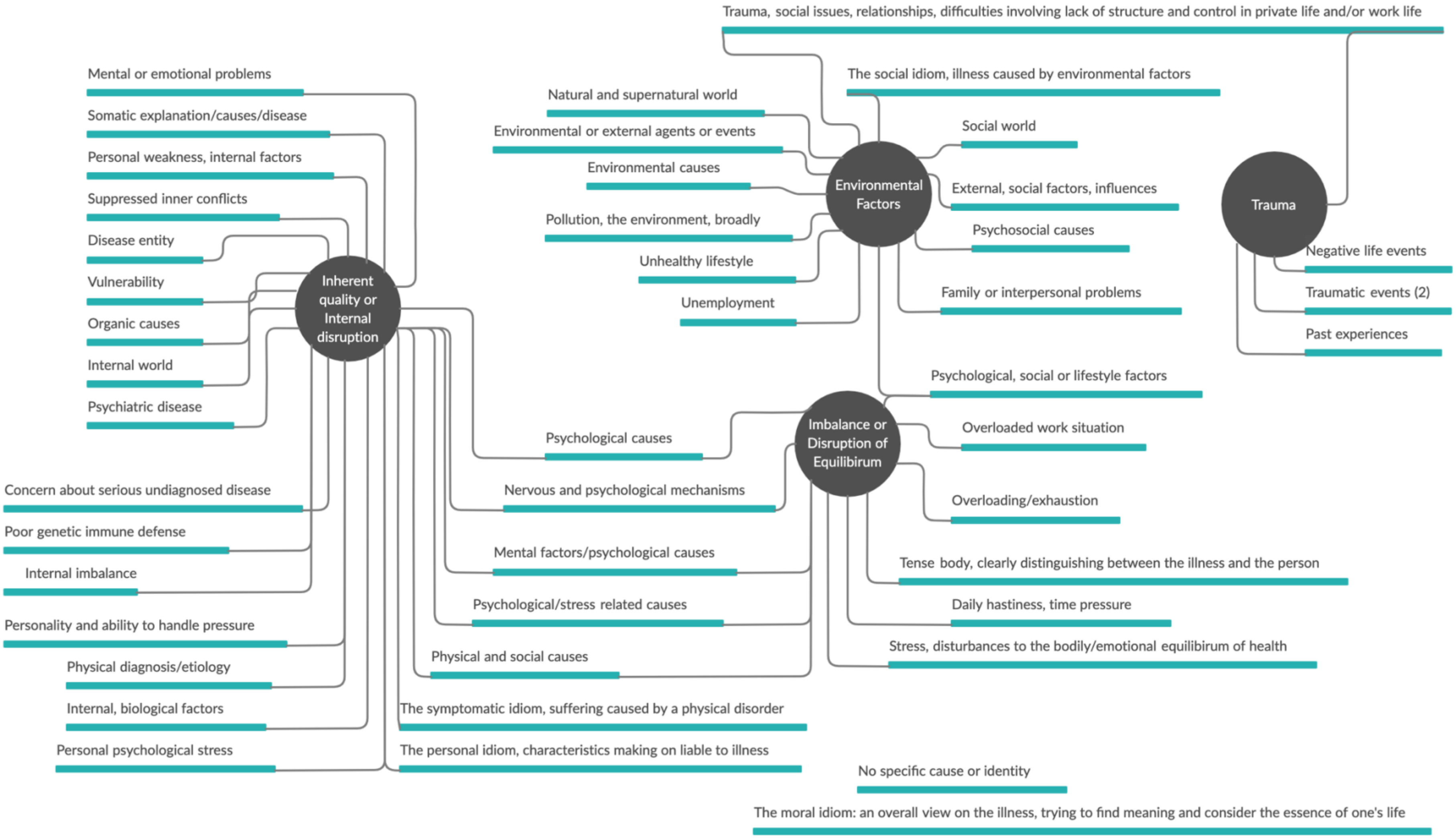
The majority of the studies found that patients had multiple explanatory models, describing complex understanding of symptoms that were fluid and incomplete or unsatisfactory to patients. (97) As the number of symptoms increased, the number of illness attributions tended to as well (66) and patients with multiple symptoms often had different attributions for each symptom. (67) All studies found that a substantial proportion of the included patients attributed their illness experiences to emotional or psychosocial causes, and in some cases, these attributions were the most common. (50,65,67,114,118) This runs counter to the belief that patients with MUS lack the insight to acknowledge their own psychological distress, or that the existence of MUS reflects a failure of patients to adequately express their distress. (79)

Through a qualitative thematic analysis of the illness attributions elicited through these thirteen studies, which are summarized in Table 2, the following four themes were determined to be an appropriate way to categorize the illness attributions for patients with MUS in primary care. 1. Imbalance or disruption of equilibrium, 2. Trauma, 3. Inherent quality of the individual, 4. Environmental factors. Figure 2 is a concept map of the explanatory models and illness attributions identified in the literature review, classified according to these four themes. Many of the themes determined by the researchers to be representative of illness attributions of patients studied fit into more than one of the categories identified in this paper. This overlap demonstrates not only the imposition of the researchers' conceptual framing of the symptom explanations, but the complexity of patients' illness narratives.

The majority of the explanatory models identified fell under the category of 'inherent quality [of the suffering patient] or internal disruption', and a number of these could also be attributed to an imbalance or disruption of equilibrium, notably stress or a feeling of overloading. Environmental factors, considered broadly to include the social world, diet, and interpersonal relationships, accounted for a sizeable proportion of the explanations, and 5 explanations explicitly related the symptoms to a traumatic event experienced by the patient. Though this categorization distinguishes between external circumstances and events and internal imbalances and personal vulnerabilities, it is likely that, given the complexity of explanatory models and the evidence that patients have multiple and fluid explanations for their symptoms, (65–67,97) this distinction is a reductive way of conceptualizing the complex, evolving ways that patients conceive of their illness experiences.

Some of the studies noted that patients attempted to make sense of their symptoms through broader perspectives in which they reflected on their life as a whole, attempting to find meaning and coherence in their illness experience through a reflection on their life's essence. (117) Concerns about inherent qualities that might render one susceptible to illness were common amongst the various explanatory models, though there are a handful of explanatory models identified that clearly distinguish the person from the illness (119) or find that more patients attribute their illness to external factors and the environment than to internal biological or psychological factors. (115) The complexity and diversity of patients' explanatory models can be visualized in Figure 2.

Figure 2: Concept map of patients' explanatory models and illness attributions for their medically unexplained symptoms



Discussion

The majority of the studies found that patients had multiple explanatory models, describing complex understanding of symptoms that were fluid and incomplete or unsatisfactory to patients. (97) Through a qualitative thematic analysis of the illness attributions elicited through these thirteen studies, these were categorized according to four themes: 1. Imbalance or disruption of equilibrium, 2. Trauma, 3. Inherent quality of the individual, 4. Environmental factors. Patients' explanatory models for their symptoms share features with many of the psychological mechanisms that have been linked to MUS, including the role of previous traumatic experiences as a risk factor, as well as personality factors such as negative affect and particular emotional regulation styles. (76)

The diversity of explanatory models revealed through this literature review, including a number of stress-, trauma-, and other psychosocial-based ideas about causation, undermines the commonly held belief by physicians that patients resist psychological explanations or fail to acknowledge their psychosocial stressors. (33) In fact, patients may readily express these to their physicians when they have the opportunity and may even be eager to discuss these as potential contributors to their illness, as will be examined through the next question. The finding that patients have several complex and fluid explanatory models for their symptoms reflects an effort to make sense of their illness experience, to find meaning in their suffering.

Literature examining hypothetical explanatory models for MUS identify several different models, including cognitive abnormalities such as an over-inclusive concept of health and misinterpretation of physical sensations. (76) Other models of MUS describe processes of somatosensory amplification, sensitisation (enhanced somatic response to sensations as a result of former experiences of these sensations), illness behaviour model, abnormal proprioception, and endocrine dysregulation. (77) Some of these theories do in fact reflect the ideas patients commonly hold about the development of their symptoms, including sensitivity theory, which suggests that some individuals are more vulnerable to develop MUS based on personality traits such as neuroticism and negative affect. (77) Others, such as illness behaviour theory, hypothesize that patients' beliefs, which are impacted by their physicians, influence their behaviour and subsequently affect physiology and symptoms, resulting in maintenance of symptoms. Others yet, such as autonomic nervous system dysfunction theory, posit a connection between psychosocial stress and MUS. (77) In short, many of the hypotheses patients have about the generation and maintenance of their MUS are quite similar to the hypotheses in the literature, suggesting a role for considering patients' insight and illness narratives as valid hypothetical models for the development of their symptoms, in addition to this being an important element of a patient-centered care (PCC) approach.

Note that this analysis and the categorization of explanatory models for MUS is confined by the methods employed in the studies. While some studies employed open-ended approaches to interviewing patients in order to elicit their explanatory models as they conceive of them, many used closed questions or allowed patients to select explanatory models from a list. Additionally, the themes identified in this critical interpretive review are heavily influenced by the ways that the idioms of distress or illness attributions were categorized and classified by the researchers in the literature reviewed, which ultimately allow the researchers to have the final say over the patients' explanatory models and how they are interpreted, rather than the patients themselves. This being said, the high degree of consistency and the presence of several of the explanatory models across multiple studies increases the internal validity of these findings, though external validity is limited by the researchers' and the method of data collection's shared influence over the interpretation of explanatory models.

This conceptual process of synthesizing the findings through critical appraisal of diverse sources of evidence (121) is incomplete without commenting on the biases endemic to literature on MUS; including the selection of patient populations as those which are deemed by physicians to have unexplained symptoms, a determination made by the physician and necessarily influenced by their perceptions of a given patient and their beliefs about MUS. Additionally, studies in which patient-physician interviews are recorded or in which patients are asked by researchers to report their explanatory models all suffer from an observer bias. This is additive to the layered observer biases from the researchers at the various stages of data collection and interpretation, including in the writing of this review. A method such as the phenomenological hermeneutic method employed by Lidén et al. (119) would likely elicit the most genuine explanatory models from patients. This study included patients who self-identified as having

MUS, with whom narrative interviews were performed by a researcher who had no prior information about the participant, and data were analyzed first through naïve reading, followed by structural analysis, then comprehensive understanding that involved theoretical and critical reflection. This approach at participant selection and interview and analysis should be employed with a larger group of patients than the 10 included in their study.

Through this critical examination and synthesis of patients' explanatory models for their MUS, we can develop an understanding of how patients conceive and make meaning of their lived illness. With this knowledge, some of the challenges of caring for patients with MUS may be addressed, as an understanding of how patients experience their symptoms may help clinicians to empathize with these patients and guide them in ways to provide care that is more responsive to the needs of patients with MUS.

Question 2:

What are patient expectations and desires when seeking care for their symptoms from their PCP, in particular with regards to explanations and communication about the nature of their symptoms? How do patients express these to their PCP?

22 articles were identified as responding to this second question; one of which (122) was added during the literature review from the reference list of another source that was excluded. (123) Two of these articles were review articles (46,124) and the remainder were largely qualitative analyses of interviews with patients. All studies considered patients in primary care or general practice, though one of the reviews (46) considered various medical settings including general practice. The data collected from these sources is summarized in Table 3.

Table 3: Summary of findings in articles responding to Question 2:

Authors	Condition, n	Methods	Results – Expectations and desires
Salmon, P., *et al.* (2004). (49)	MUS, n=36 patients Identified by GPs	Qualitative analysis of audiotaped consultations, inductive analysis.	34/36 patients provided opportunities for GPs to address psychological perspectives through opportunities for explanation, explicit requests, statements of uncertainty or worry, by proposing serious illness or normalising explanations. GPs disregarded most of these opportunities 23/36 provided opportunities to address emotional or social problems by discussing life events, stress, mood or depression. These were either facilitated, or blocked by GPs disregarding the clue, re-asserting a symptomatic agenda, normalising or emphasizing the patient's responsibility for the problem.
Ring, A., *et al.* (2004). (37)	MUS, n=36 patients Identified by GPs	Qualitative analysis of audio recorded consultations, inductive analysis.	Overt demands for somatic intervention were rare. Patients expressed impairment of daily activities, intensity of symptoms, physical explanations, emotional distress and fears. 17/36 patients indirectly negated the GP's attempts to explain or manage their symptoms, in particular to exclude disease.

Ring, A., *et al.* (2005). (50)	MUS, n=420 identified by GPs	Qualitative analysis of audio recorded consultations. LCIAS to quantify the types of verbal communication.	Most patients indicated psychosocial problems, either disclosing them directly or suggesting psychosocial explanations for their symptoms. Most patents explicitly prompted explanations for their symptoms, and most also offered explanations of their own. 95% provided at least one of these types of cues to psychosocial need.
Salmon, P., *et al.* (2005). (33)	MUS, n=357, identified by GPs Controls, n=357	Multilevel analysis comparing patients with MUS to patients with explained physical symptoms	Patients reported the extent to which they wanted somatic intervention (SI), emotional support (ES), explanation and reassurance (E&R): Patients with MUS sought more ES than controls but no more E&R or medical investigation and treatment (SI). Older patients sought less support, less information and reassurance, but more investigation and treatment. Gender not significant.
Nordin, T. A. *et al.* (2005). (122)	Unexplained Symptoms, n=47	Qualitative study of semi-structured interviews with patients and clinicians, coded using thematic analysis of narratives.	Patients with MUS identified goals, outcomes and details of their care. Primary patient goals were: - Cause identification, explanation (15%) - Symptom alleviation, hope for a cure (28%) - Clinician support; caring, understanding, validation (62%) - Patient coping, knowing cure was unlikely (43%) - Functional improvement (45%)
Junod Perron, N. & Hudelson, P. (2006). (114)	Somatisation, refugees and asylum seekers n=26	Semi-structured interviews. Qualitative analysis of key themes in narratives.	Patients formulated their suffering in both medical and social/legal terms. They sought help from physicians for both types of problems. Patients emphasized the importance of being examined & doing tests (14/26) and receiving medical treatment (23/26) 6/26 patients looked to physicians to help resolve social problems
Salmon, P., *et al.* (2006). (125)	MUS, n=420 identified by GPs	Qualitative analysis of audio recorded consultations coded using the LCIAS. Hierarchical logistic regression analysis	Patients' speech was categorized into four groups (LCIAS categories of presentations (mean occurrences per consultation)): - Symptoms: new problem, elaboration, catastrophization (15.98) - Psychosocial: explanation, new or elaborate disclosure (6.14) - Disease explanation (1.81) - Somatic intervention proposal: advocate somatically oriented prescribed drug, test/investigation, referral, nonspecific. (2.30)
Salmon, P. *et al.* (2007). (126)	MUS, n=249, identified by GPs	Multilevel regression analysis of utterances, audio recorded consultations coded using the LCIAS.	Three major types of help that patients seek from their GPs, identified from 22-item version of the patient request form: - Medical investigation and treatment - Explanation and reassurance - Emotional support
Salmon, P., *et al.* (2007). (127)	MUS, n=326, identified by GPs 33 GPs	Prospective naturalistic study. Patient self-report, audio-recording and coding of speech in consultations using LCIAS, and multi-level regression analysis	Patients' desires for emotional support was associated with increased psychosocial talk, including disclosures of psychosocial problems, psychosocial causes of symptoms and requests for help with psychosocial factors contributing to symptoms. Patients who wanted reassurance suggested more physical explanations, including disease. They did not overtly request explanation. Patients wishing for somatic intervention (investigation and treatment) was associated only with their talk about details of such interventions and not explicit requests for them.
Sumathipala, A. *et al.* (2008). (116)	MUS, 5+ symptoms of any duration n=68	Short Explanatory Model Interview (SEMI). Qualitative & quantitative analysis of structured interviews.	"What do/did you hope to gain from seeing doctors? What did you expect/want the doctors to do?" 50% of patients specifically wanted the doctors to make them better 13% wanted advice and explanation. 12% wanted medications. 9% wanted a diagnosis. 9% wanted further investigations. None requested referral to a specialist.
Kappen, T. & van Dulmen, S. (2008). (128)	MUS, first visit. Patients identified by GPs according to a 5-point scale of psychological impact on symptoms, n=97	Video recordings of consultations, categories of patient presentations developed from descriptions in the literature (129)	Most patients presented their symptoms alongside an underlying concern. Classes of presentations: 1. Symptoms only (12.1%) 2. Symptoms with clue to underlying concern (68.0%) 2A. Objectifying symptoms (18.2%) through relating to cause (medical, psychological/social) or to solution (self-medication, lifestyle, request investigation or treatment) 2B. Justifying symptoms (37.9%) through convincing (with syndromal pattern, vivid descriptions or exaggerations) or through explanation (personal/family story or medical history) Both 2A and 2B: 43.9% 3. Symptoms with explicit concern (20.6%) such as direct question, fear of specific disease, statement of worry or uncertainty

Morriss, R. & Gask, L. (2009). (124)	MUS	Review	Patients seek recognition of their distress, emotional and practical support, alliance and understanding from their GP, and to feel that their GP considers their problems legitimate concerns and does not blame the patient or consider them wasteful of the GP's time. They use graphic and emotional language in an attempt to convey the reality of their suffering, describing effects of symptoms on their daily living. They offer biomedical explanations or attribute symptoms to emotional distress.
Peters, S. *et al.* (2009). (130)	MUS GPs trained in reattribution (n=16). Control (n=7). n=23 patients selected for at least 3 months of MUS	Qualitative study, thematic analysis of in-depth semi-structured interviews	Patients presented multiple complex, seemingly unconnected issues and a range of reasons for consulting, which they struggled fully express, and often simplified in the consultation, aware of their limited time. Some patients sought explanations, while held explanations that they wanted confirmed through investigation or medication. Others sought support with self-management. Most patients' explorations already incorporated psychosocial factors and did not impose a dichotomy between psyche and soma. Patients regarded GPs as having less sophisticated views than their own. Discomfort and fear of burdening the GP prompted patients to avoid disclosing emotional problems.
Risør, M. B. (2009). (117)	MUS, n=9 Patients identified by GPs	Repeated, semi-structured, qualitative interviews. Thematic content analysis on a pragmatic and phenomenological basis	Patients employ at least four different explanatory idioms: - The personal idiom, - The social idiom, - The moral idiom. - The symptomatic idiom: refers to talking about and trying to find a cure for the symptoms. Mainly in primary care. Informants in the early stages of MUS often rely on this idiom in their search for explanations.
Nunes, J. & Ventura, T. (2013). (118)	MUPS, 6 months following diagnosis, n=15	Qualitative analysis of interviews, semi-directive method, some open questions, some scripted.	Patient expectations of the consultation: To undergo diagnostic tests (8/15), to be given medication (3/15), diagnosis or explanation (3/15), 'help' or 'advice' (4/15) To be listened to and to receive 'attention' and understanding (5/15)
Lidén, E., Björk-Brämberg, E. & Svensson, S. (2015). (119)	MUS, n=10 Patients with at least 50% of reported symptoms medically unexplained.	Phenomenological-hermeneutic method, narrative interviews. Qualitative study.	"The participants wished that the healthcare professionals would listen to their experiences and discuss their interpretation of symptoms. At times the opportunity to describe their experiences appeared to be more important than receiving a diagnosis: […]" "I would like them to listen more instead of trying to put a name on it." Search for explanations involved a wide range of psychological, social, cultural and organization perspectives. "[Patients made] efforts to find meaning […] illustrated in their narratives of trying to verbally express, to themselves and others, how they experienced their bodily sensations and how these affected them as people." Illness narrative may be therapeutic, apprehending and formulating the experience in a comprehensive way to themselves and others.
Kornelsen, J. *et al.* (2016). (131)	MUPS, n=38 participants who voluntarily enrolled	Phenomenological study, interpretive approach, open-ended interviews	For most participants, when early investigations did not yield a diagnosis, they described a conflicting sense around the need for continued investigations, relief that nothing had been discovered, balanced with anxiety when a definitive cause was not found. They described the importance of naming as a crucial step in the social validation of their condition, the economic burden of their illness. "Part of the importance of naming [...] derived from the consequences of *not* naming: that is, a sense of not being believed." Emphasized the importance of therapeutic relationships, the provider respecting the reality of the symptoms, making the patient feel heard. Participants with a greater degree of acceptance of their symptoms tended to value acceptance in care providers and tolerate uncertainty more readily, turn their attention towards managing symptoms.
Houwen, J. *et al.* (2017). (36)	MUS, n=39 patients identified by GPs	Qualitative (inductive) analysis of semi-structured interviews. Video-supported simulated recall of consultation.	Patients wished to have their agenda explored and to discuss what they deem to be important, have the opportunity to tell their story in its entirety, for GPs to pay more attention, not interrupt. They expected from their GPs: - Empathy, non-verbal shows of attention - Specific plan or advice for after the consultation - That they prepare and remember what they had previously discussed - Open-mindedness, discussion of the patient's view on the symptoms - Acknowledgement from the GP of their limited understanding of the origin of the symptoms. Honesty about lack of certainty

Houwen, J. *et al.* (2017). (132)	MUS, n=39 patients identified by GPs	Qualitative interviews with MUS patients in which they reflected on their video-recorded consultations. Constant comparative analysis	All patients said they wanted to be taken seriously for the symptoms for which they were seeking help. Feelings of being taken seriously are enhanced when the GP: - Pays empathic attention to them as individuals, knows their personal circumstances and has an open, empathic approach - Ensures a good conversation, with non-verbal cues of attentiveness, no interruptions, treats patient as an equal partner - Is attentive to their symptoms by exploring these in depth and acting on them. Attends to patients' ideas, thoughts and fears. Some mentioned the need for a clear explanation of the cause. Others preferred the simple reassurance of excluding serious diagnosis.
Sowińska, A. & Czachowski, S. (2018). (65)	Diagnosis of distinctive somatoform disorders, >2 years of symptoms n=20	Qualitative content analysis of filmed semi-structured interviews.	Most respondents had no expectations from the healthcare system, sought care elsewhere and admitted to disengaging from medical services, noting that extra tests would not reveal anything new. Few patients expected the legitimization of their symptoms. They wished to be taken seriously, not be dismissed. Most did not expect that their symptoms would be treated on par with physical symptoms.
Dwamena, F. C., *et al.* (2019). (120)	MUS, n=19	Verbatim transcripts of interviews, iterative consensus building process of analysis. Qualitative study, grounded theory.	Patients identified as 'coping high utilisers', who had a significant degree of psychological insight, primarily sought explanations. Those identified as 'classic high utilisers' had little psychological insight, and sought primarily symptom relief, legitimization, and support. Patients identified as 'worried high utilisers' were more anxious about their health and demanded excessive care and complained when they perceived resistance to their expectations and demands.
Stortenbeker, I. *et al.* (2020). (46)	MUS in medical settings, varied criteria, n=18 publications. 5 in general practice.	Systematic review, 18 publications, linguistic and interactional analyses, synthesis according to the principles of meta-ethnography.	Patient pursue recognition for their symptoms through: - Recognition of symptoms as real and potentially severe, claiming legitimacy by presenting symptoms as worthy of medical attention. - Intense language to illustrate severity of complaints - Description of abnormal, involuntary symptoms that threaten their functioning - Referral to previous issues to emphasize need for medical attention - Focus on pervasive consequences of symptoms

Synthesis of results:

Most of the studies examining patient expectations and desires regarding their need for care from their PCPs were qualitative analyses of recorded consultations or interviews with patients analyzed qualitatively. Some of these studies were conducted on the same group of patients, using the same data, but investigating different questions and analyzing different dimensions of their collected data. The patients with MUS were identified by their PCPs based on similar sets of criteria, which generally required the presence of symptoms causing clinically significant distress or impairment, over a few months and not explainable by physical disease. The results responding to patients' expectations and desires for care are reported here under two broad categories: A. hints and implicit clues to patients' needs and desires from their medical care, and B. explicit requests for care and patient-identified goals and expectations of care.

A. Hints and Implicit Clues

Hints that patients provide to their desires from medical care are found in the disclosures patients make to their PCPs and the concerns that they express. Most articles reported patients expressing psychological and social perspectives on their symptoms through means such as direct disclosure of psychosocial problems or suggestions of psychosocial explanations. (37,125,127) Others found that patients conveyed what they hoped the PCPs would address through references to underlying concerns that were quite varied, including relating their symptoms to underlying medical, psychological or social causes or fears of specific diseases, (128) suggesting biomedical explanations or attributing symptoms to emotional distress, (124) or references to stress, mood and life events. (49) The complexity and range of these concerns and reasons for consulting was found to be simplified by patients, in an attempt to have the most important issues addressed within the limited available time of the consultation. (130)

In addition to expressing what they wish to have addressed through reference to their concerns about the nature of their symptoms, patients frequently expressed the severity of their symptoms and the impact that the symptoms have on their functioning as a means of claiming legitimacy for their symptoms or to ensure that their suffering is appreciated by their PCP. Several studies reported on attempts made by patients to convey the reality of their suffering and efforts made to assert their legitimacy in their quest for medical care. In a 2009 review by Morriss & Gask, it was noted that patients attempted to convey the reality of their suffering to their doctor by using “graphic and emotional language to describe symptoms” and emphasising the “effects of symptoms on [their] daily living (e.g. can’t sleep, so can’t work)”. (124) In a study that linked patients’ self-reported expectations from the consultation with their disclosures in the consultation, it was found that patients’ desires for emotional support were associated with increased psychosocial talk, including requests for help with psychosocial factors contributing to symptoms, while those who wished for reassurance suggested physical explanations, including diseases, and those who wished for somatic intervention discussed details of these interventions in the consultation (127). Some patients were uncomfortable and concerned about burdening the GPs with emotional problems, so they avoided disclosing them. (130)

A 2020 review by Stortenbeker and colleagues noted that patients used intense language to illustrate the severity of their symptoms, they emphasized the abnormal and involuntary nature of their symptoms and implied how these threaten their functioning, focusing on the consequences of their symptoms. The practice of justifying the legitimacy of symptoms also took the form of vivid descriptions or exaggerations, referring to complex patterns of related symptoms, (128) elaborating on mentioned symptoms and catastrophizing. (125) Efforts to assert the legitimacy of their symptoms and make clear to their PCP that they require medical care are common amongst patients with MUS.

B. Explicit Goals and Requests for Care

With regards to explicit requests for care and patient-identified goals and expectations from their PCP, these were ascertained in studies either directly, by asking patients with MUS to identify their goals of care, or by inferences made by the researchers through examination of the speech of patients in primary care. These can be categorized based on Nordin and colleagues' grouping of the goals of care identified by patients, as follows: (A) Explanation, identification of cause of symptoms; (B) Listening, honesty and attention; (C) Support, validation, care, empathy and understanding from clinician; (D) Coping and functional improvement; (E) Cure, alleviation of symptoms (122) with an added category of (F) Somatic investigations and interventions.

Nearly every study investigating patient expectations found that patients expected (A) explanations for their symptoms and identification of their cause. (49,116,118–120,122,124,126,132) However, in a comparison of patients with MUS and patients with medically explained symptoms, it was found that patients with MUS did not expect explanations any more than did their explained symptom counterparts, (33) though it is important to note that patients were asked about their desire for explanation in combination their desire for generic reassurance. It was repeatedly reported that patients wished for their PCPs to (B) listen attentively and communicate with them honestly, (36,118,119,131,132) with references to making the patient feel heard and ensuring shows of attentiveness through non-verbal cues and avoiding interruptions, (36,132) and noting the therapeutic value of listening itself, rather than its role in leading towards a diagnosis. (119) Patients frequently expressed (C) the importance of empathy and support from their PCP and validation and understanding of their suffering. (33,65,118,120,122,124,126,131,132) Three studies commented on patient's desires for (D) help with coping with their symptoms, and aspirations for functional improvement, (116,120,122) and only two found that patients expected (E) a cure or alleviation of their symptoms, (117,122) with Nordin and colleagues finding that more patients had the goal of coping than of symptom alleviation and hope for a cure, and that many understood that a cure was unlikely. (122)

There was conflicting evidence on patients' expectations for (F) somatic intervention, which was difficult to concretely define, as many studies combined investigations and medical treatment within the umbrella of somatic intervention. Ring and colleagues found that overt demands for somatic interventions were rare, (37) and Salmon and colleagues found that somatic intervention (investigation and treatment) were equally and infrequently expected by patients with MUS and those with symptoms deemed medically explained (33) and in another study by Salmon and colleagues, it was found that advocating for somatic intervention was infrequent. (125) In contrast, a study of somatisation in refugees and asylum seekers from Yugoslavia, found that the majority of patients expected medical treatment and just over half emphasized the importance of being examined and doing tests. (114) Other studies found that many patients emphasized the need for appropriate investigation (124) and undergoing diagnostic tests, (118) while only a handful wished for medications. (116,118) Dwamena and colleagues found that patients with a high degree of worry wished for more medical care. (120) Similarly, in a 2020 review, Stortenbeker et al. found that patients emphasized a need for medical attention, (46) though in neither case is it made clear specifically what patients expected with regards to this medical attention and care. In a phenomenological investigation of patients' experience of prolonged uncertainty in diagnosis, patients described a conflicting sense around the need for continued investigations when initial investigations were negative, "balancing relief that nothing had been discovered with anxiety when a definitive cause was not found." (131) Many of these studies were conducted on patients with MUS who had been seeking care over a long period of time, so it is important to note that their expectations for care are necessarily impacted by their existing relationship and history with their PCP in the context of their MUS.

Discussion

Patients with MUS express numerous concerns about their symptoms that can be used as underlying clues as to their expectations from their primary care providers. These concerns span the realm of psychological, social, and biological perspectives on their symptoms, and may be disclosed explicitly, such as by hypothesizing about an underlying disease causing their symptoms, or implicitly, such as by alluding to social or psychological stressors and their relation to the symptoms they are experiencing. The diversity of explanatory models that patients with

MUS use to make sense of their suffering are reflected in the varied ways that patients hint at their underlying concerns about their symptoms and provide clues to their PCPs as to what they wish to have addressed in the consultation. The psychological concerns that patients express about their symptoms subvert the widely held, longstanding view of researchers and physicians that patients deny the psychological distress that may contribute to their symptoms. (33) In fact, not only do patients engage with psychological explanations for their symptoms and consider that they may be related to psychosocial stressors and personal vulnerability to these stressors, they also make it clear in the consultation that they are concerned about psychological factors that may contribute to their symptoms.

The worries that patients express about their symptoms can be seen as a way of directing the PCP towards addressing what is most unsettling or bothersome about their illness, as an invitation for the PCP to engage with their suffering. This invitation is notably complemented by the various attempts that patients with MUS make to have their concerns taken seriously, whether by employing exaggerated language or embarking in complex narratives about their symptoms, or by using different means to demonstrate the severity of their suffering and the life-altering impact of their symptoms, or by emphasizing the abnormal and involuntary nature of their MUS. (46) These efforts to assert their legitimacy are reflective of the challenges that PCPs face in caring for patients with MUS, and how these are manifested in the clinical consultation. Given that the majority of the studies reviewed in this section were conducted on patients who had at least a few months of visits with their PCPs regarding MUS, these appeals to attend to their suffering can be seen as reflective of PCPs failure to do so. Further, the emphasis on the involuntary nature of symptoms may be seen as a strategy that patients employ to absolve themselves of guilt or responsibility for symptoms for which they feel they have been blamed.

Inadequate or inappropriate care from PCPs for patients with MUS is multifactorial, and likely reflects the common cultural expectations that patients with MUS are frustrating and demanding, as well as PCPs' lack of knowledge about what patients with MUS expect from them. While PCPs have been found to take more time in MUS consultations than in those with patients with medically explained symptoms, this additional time is not spent on exploration of patients' concerns, worries, beliefs, and impact on their overall functioning and quality of life. (43) PCPs' lack of awareness of how to respond to the needs of patients with unexplained symptoms may be related to limited literature on the topic, as one of the first studies that directly engaged with MUS patients in order to identify relevant communication elements within the consultation was published only in 2017. (132) This being said, the accumulated evidence collected on the topic in the last five years, as well as a recent systematic review of the evidence on linguistic and interactional aspects that characterize MUS consultations (46) have made it quite clear what patients with MUS expect from consultations with their PCPs, as well as underlining the reasonable expectations of these patients, such as attentive listening and honest communication, empathy and support, and help with coping and alleviation of their symptoms. Contrary to common belief by physicians, patients do not demand somatic intervention, (37) and in fact, PCPs may provide somatic intervention not in response to overt patient pressure, as it is so often claimed, but rather due to their own uncertainty about how to care for the patient with MUS. It is important, then, that physicians listen to the implicit and explicit clues that patients provide as to their desires for care. In fact, physicians' own attributions of somatic intervention to patient pressure may be better seen as justifying their interventions rather than explaining them. (51,125) The accumulated evidence reviewed on the subject of MUS in primary care demonstrates that patients wish to be understood, cared for, and validated in their suffering.

The evidence reviewed is limited by a number of factors related to observation, including social desirability bias impacting patients' responses in their interviews. Generalization of the evidence on patients' expectations and desires for medical care from their PCPs is limited by the population of patients included in the reviewed studies. In those studies in which GPs identify patients with MUS based on a given set of criteria, (37,49) they may be selecting those with the most obvious symptoms or the most egregious presentations of unexplained symptoms, potentially favouring those who they feel have psychosomatic causes for their symptoms, given that this is a common understanding of that to which MUS refers. (28,48) Furthermore, with the exception of one study (128) which examined the underlying concerns of patients when presenting their symptoms during an initial presentation of MUS in primary care, the remainder of the studies reported on patients who had at least several months of symptoms and a corresponding long-term relationship with their PCP, resulting in contamination of patients' ideas with those of their physicians. (118) The concerns these patients bring regarding their MUS are informed by their experiences with their PCPs, including those that have been addressed and engaged with, and those that have not. That is to say that long-ignored concerns may have been brushed aside by the patient in favour of more pragmatic desires for care, or alternatively, they may be brought to the fore due to repeatedly being neglected. In addition, the long term nature of these patients' MUS may result in an underreporting of their desire for explanation, as expectations with regards to explanations may have been set during previous interactions with their PCP. (36) This may also be reflected in patients' awareness that a cure may not be possible, (122) and understanding that they have likely developed after repeated consultations with their PCP. Sowińska and Czachowski's 2018 study of patients with at least 2 years of unexplained symptoms is especially illustrative of this phenomenon, as patients reported having no expectations from their general practitioner, notably disengaging from medical services and expecting only that they be taken seriously, but not that their symptoms would be treated on par with physical symptoms. (65) While no studies to date show the evolution of the expectations of MUS patients over time, it may be inferred that as they receive care that fails to respond to their needs, they undergo a response-shift reflecting the care that they are receiving, seeking out other sources of care. Alternatively, patients' expectations of their PCPs may continue to mount as their PCPs repeatedly fail to engage with their desires for care. It would be worthwhile to conduct a longitudinal study of patients' expectations from their PCPs while simultaneously examining the care that they receive and how these co-evolve over time.

Question 3:

How do PCPs communicate and explain MUS to patients, and what challenges arise in the communication with patients regarding MUS? How do patients perceive these explanations?

23 articles were identified as responding to this third question. The majority were qualitative analyses of consultations or of interviews with physicians. Three were secondary data sources; two review papers (46,103) and one editorial. (123) Given the breadth of the data collected from the critical review of these articles, the summary of the data in Table 4 is selective, reflecting that which responds to question 3 through either a review of types of explanations and normalizations provided for symptoms or through an analysis of the structure of the dialogue

within the consultation. Other information regarding management strategies is briefly reviewed in the synthesis of results. Some information is included in the table to contextualize the findings.

Table 4: Summary of selected findings in articles responding to Question 3

Authors	Condition, n	Methods	Results – Communication and Explanation
Dowrick, C. F., *et al.* (2004). (80)	MUS, 21 GPs, 36 patients with MUS identified by GPs	Qualitative analysis of audiotaped consultations, inductive analysis	In 78% of the consultations, GPs normalised patients' symptoms. Normalisations were categorized into three types based on effects: 1. Normalisation without explanation: dismissal of the presence of disease, rudimentary reassurance, appeal to the authority of a negative test result - Patients were not reassured and responded by a more elaborate, robust presentation of their symptoms, or introduced new problems. - Associated with an increased likelihood of somatic management 2. Normalisation with ineffective explanation: explaining symptoms via a tangible physical mechanism not linked to patient concerns. Implied that healthcare intervention would be minimal or unnecessary. - Responses were similar to normalisation without explanation 3. Normalisation with effective explanation: tangible mechanisms emerged from dialogue, some with links between physical and psychosocial factors - Enabled discussion of psychological or social problems and ways for patients to take responsibility for symptom management.
Ring, A., *et al.* (2005). (50)	Patients with MUS identified by their GPs, n=420, 36 GPs	Audiotaped consultations, LCIAS to quantify types of verbal communication.	Half of the GPs normalized symptoms by indicating the absence of physical disease. Two thirds provided explanations other than physical disease, though most also suggested physical disease might be present. 16% of GPs offered verbal empathy when communicating with patients
Epstein, R. M. *et al.* (2006). (43)	MUS, 100 PCPs, 2 covert SPs portraying the GERD role and the MUS role	Audio recorded consultations, analysis using the measure of patient-centered communication (MPCC)	MUS yielded significantly lower scores on MPCC component 1, physicians' exploration of the patients' experience of illness. Patients' symptoms were not explored as fully, and validation was less likely. Components 2 (exploration of psychosocial context) and 3 (attempts to find common ground on diagnosis and treatment) were unchanged.
Salmon, P., *et al.* (2006). (125)	MUS, n=420 identified by GPs 36 GPs	Audio recorded consultations coded using LCIAS. Qualitative, hierarchical logistic regression analysis	GPs proposed somatic intervention a mean of 4.86 times per consultation and further consultation a mean of 1.30 times per consultation. The probability of explicit somatic proposals increased as patients added to their symptom presentation and decreased after they added to their psychosocial presentation.
Salmon, P. (2007). (103)	MUS	Narrative and critical review	Three typologies of the clinical consultation were identified: 1. Contest: patients seek legitimacy for their problems, and GPs respond with normalisation (simple reassurance that does not engage with the details of the patients' concerns), disregarding cues to psychosocial problems, declining 'empathic opportunities'. Patients may intensify their accounts, and GPs may eventually propose somatic intervention. 2. Collusion: GPs simply accept patients' explanations or treatment suggestions. Simple acquiescence can undermine patients' confidence in their GP's expertise as these are often suggested tentatively. 3. Collaboration: seeking common ground with the patient and developing an agreed-upon explanation
Salmon, P. *et al.* (2007). (126)	MUS, n=249 patients, identified by GPs. 34 GPs.	Audio recorded consultations. Dependant variable: occurrences of D-CP code[3]. Multilevel regression analysis.	The GPs responses on the patient-centeredness scales were high. Criticism was recorded in 27.1% of consultations and was more likely when patients sought more emotional support. Criticism was positively associated with GPs beliefs in sharing responsibility with patients and to GPs positive model of themselves. It was inversely associated with GPs belief that patients' feelings were legitimate business for consultation.
Anderson, M. *et al.* (2008). (134)	MUS >6 months, n=49 patients, identified by n=36 GPs from memory.	Qualitative study of interviews with physicians and patients. Thematic analysis	Management strategies were classified into seven themes: (1) Providing medical treatment, (2) listening attentively, (3) validating complaints, (4) demonstrating commitment through frequent, regular visits while limiting spontaneous access to care, (5) explaining symptoms and plans for care while discussing uncertainty, (6) exploring causes of symptoms with tests or referrals, (7) communicating GPs confidence

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[3] D-CP code: 'doctor criticizes patient', which "refers to specific statements that could be heard by patients as critical of something they have said or done." These statements do not necessarily indicate negative feelings toward patients, in " […] sociolinguistic theory, criticism is a means by which a speaker challenges the assumptions that another person seems to be making about the purpose of an encounter or about participants' roles in it." (133)

Kappen, T. & van Dulmen, S. (2008). (128)	MUS, first visit. Patients identified by GPs according to a 5-point scale of psychological impact on symptoms n=97	Video recordings of consultations, categories of GP responses based on Floyd et al. (129) supplemented by (49,80).	GPs responded to patients' symptoms, clues or concerns by: 1. Ignoring (6.2%): i.e.: continuing on a different subject, a physical examination, or no verbal response. 2. Not exploring (24.7%) i.e.: normalisation, pointing out responsibility, expressing own emotions, basic acknowledgement, or humor. 3. Exploring (79.4%). Three types: A. Non-directional: asking more about patient's situation. B. Clue-exploration: direct question or reflection on underlying worry C. Medical exploration through reflection, open or closed questions to gather more information, avoiding the clue or concern.
Olde Hartman, T. C. *et al.* (2009). (42)	MUS Purposive sample of 22 GPs	Focus group Interviews, analyzed qualitatively using constant comparative analysis	GPs often feel incapable of explaining symptoms, and attempt to by: 1. Telling patients that there is no disease, stating 'nothing is wrong' 2. Using metaphors to provide insight into hypothesized interactions between symptoms and psychosocial life, often a tangible physical mechanism indicating an imbalance between load and capacity 3. Normalizing the symptoms, stating that symptoms are a part of life GPs attempt to maintain the relationship by clarifying the link between somatic experiences and psychosocial circumstances of the patient. If unsuccessful, they model the relationship in one of three ways: 1. Mutual alliance: providing ritual care, aware of the consequences of unnecessary interventions, intending to preserve a good relationship. 2. Ambivalent alliance: same rituals as the mutual alliance model, but the GPs are unhappy with the situation. 3. Non-alliance (rare): cutting off all reasons for encounter by taking a cool, objectifying medical gaze. Communicate the negative finding (of absence of somatic explanation for the symptoms) and indicate that the patient should not consult with these kinds of problems.
Olde Hartman, T. C. *et al.* (2013). (135)	MUS, n=20 consultations with 20 unique patients and family physicians	Video-recorded consultations analyzed qualitatively using constant comparative analysis. Quantitative analysis of text in the transcript.	90% of consultations included discussion of patients' beliefs and concerns, 55% included consequences of the symptoms on patients' daily activities, social environment and illness behaviour. Most were initiated by patients. All consultations included explanations, though most did not incorporate patients' expressed beliefs and concerns. Reassurance was not focused on the patients' concerns. In 50% of consultations there was no in-depth inquiry of the presented symptoms.
Nunes, J. & Ventura, T. (2013). (118)	MUPS 6 months following diagnosis. n=15	Qualitative analysis of semi-directive interviews, some open questions, some scripted	Normalisation without explanation appeared to be effective in a trusting therapeutic relationship that may dispense with the need for words. In a new therapeutic relationship, it was associated with the lowest level of satisfaction.
Aiarzaguena, J. M., *et al.* (2013). (136)	MUS, n=26 patients, 18 family physicians	Qualitative, naturalistic observational study of 11 sequences of explanations, analyzed using conversation analysis. DEPENAS communication intervention (137)[4]	Symptom explanations (SEs) based on hormonal alteration was: 1. General: not discussing situations specific to the patient 2. Specific: GPs discussed the patient's own life events Some GPs encouraged patient responses. Only after the completion of the symptom explanation did they seek elaborated patient responses through broad questions/appeals. Patients' responses followed 5 patterns During the SE: 1. Silence, head nods, continuers such as "mm hm," 2. Simple agreements, and 3. Extensive agreements After the SE: 4. Verbalized resistance and 5. Psychosocial statements in which patients either related their well-being and quality of life with emotions or situations or reflect on their psychological internal worlds.
Hansen, H. S., *et al.* (2013). (138)	MUS, purposeful sampling, n=28 GPs	Grounded theory approach, focus group interviews with GPs	Three consultation types emerged, influenced by the GP, the patient, and contextual factors, which, in turn, affected the diagnostic process: 1. Searching for a disease: following a traditional biomedical approach, the GP uses medical investigations in search of treatable conditions. Rare opening for psychological or social explanations, and patient's psychological or social clues are usually ignored. Emphasis on thorough assessment to localise the pathology. GPs rationalize this as a need to know that the patient was properly assessed to begin with. 2. Going by the routine: GP examines and diagnoses the patient, following the structure of biomedical consultations, taking a pragmatic approach

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[4] The DEPENAS communication intervention consisted of a "communicative strategy to obtain the patient's permission to conduct a psychosocial exploration, physicians were trained to discuss with patients the possibility that symptoms were the result of a hormonal alteration caused by the perception of life events and experiences. The goals of the hormonal explanation were (1) to work as an introduction or a bridge to open a conversation of psychosocial issues with the patient, as part of a structured psychosocial intervention; and (2) to communicate to patients that clinicians believed that patients' suffering was real without imposing a diagnostic category." (137)

			that addresses only the physical side of the problem to make an easy consultation. The GP does not respond to cues from the patient. Hopes to avoid medicalization and avoid imposing a sick role upon the patient. Use of normalisation. 3. Following various paths: the GPs simultaneously consider physical, psychological, and social explanations for the symptom through an ongoing dialogue with the patient. Physical assessments are made mainly to reassure the patient. Assumes the patient's cooperation and openness to other explanations and their acceptance of the complexity of the problem. Negotiating towards a shared understanding. Includes educating the patient on the meaning and management of symptoms.
den Boeft, M. *et al.* (2017). (139)	Moderate MUPS 112 consultations (n=39 patients, 5 GPs)	Transcripts of audio recorded consultations, constant comparative analysis to classify dialogue types and outcomes from two studies of Symptoms Clinic Intervention: consultation intervention for MUPS in primary care	4 dialogue types were identified within 115 explanation sequences (ES) 1. Lecture (6%): GP spoke in blocks of speech, allowing minimal patient input, controlling content. Little effort to customize ES to patient. 2. Storytelling (40%): primarily GP-led, but more interactive, informal, and more often customized, including personally relevant details from patients' account, checking back by GP. 3. Contest (16%): struggle for control of dialogic space, centrifugal dialogue with a multiplicity of accounts and disagreements. Both GP and patient contributed ideas and strove to occupy the dialogic space, with explicit counter statements, blocking techniques. 4. Deliberation (38%): greater engagement between GP and patient, both contributing ideas, centripetal forces within the dialogue, parties worked towards a mutually acceptable explanation. Eight outcomes of the ES were identified. Completed, concluded ES were either accepted or rejected. Completed ES without definitive conclusions ended in patient self-affirmation, mis-affirmation or holding. Incomplete ES were either engaged with and followed by transition to a new topic, or not engaged with by the patient at all.
Morton, L., *et al.* (2017). (140)	MUS, n=38 patients, 5 GPs	Constant comparative analysis to develop a taxonomy of explanations from two studies of Symptoms Clinic Intervention: consultation intervention for MUPS in primary care	138 explanations were categorized based on who was given agency over the symptoms and overall emphasis of the symptom explanation. 1. Rational adaptive (22.5% of explanations, used with 50% of patients): describing symptoms in terms of biological or psychosocial processes that caused and/or perpetuated symptoms. Implied that processes over which the patient has agency are the main perpetuating factors. 2. Automatic adaptive (37.0% of explanations, used with 66.6% of patients): clearly linking a stimulus (involuntary process, typically physiological) to its consequence, the symptoms. Processes acting maladaptively to generate and/or perpetuate symptoms. Agency given to the body or brain, places the causal responsibility away from the person; "create distance between the patient and problematic body, which is typical of conventional biomedical clinical interaction." 3. Complex (37.7% of explanations, used with 66.6% of patients): no clear link between a stimulus and its consequence, no adaptive purpose or rationale for symptoms. Symptom generation located within the intricate functioning and/or interplay of different body systems. Gave agency to systems which were complex and therefore unknowable, 'vicious cycles.' Essentially non-adaptive and without purpose. Mirroring often-chaotic narratives of patients with MUS. The implicit lack of agency in these accounts limits therapeutic options. 4. None of the above (14.5%): generally simple relationship between causes and resulting symptoms, not situated in any larger processes. Components of the explanations: Facts (present in 52.2%), causes (present in 63.8%) and mechanisms (present in 93.5%).
Sirri, L., *et al.* (2017). (105)	MUS, 433 Italian GPs	Structured questionnaire	GPs management strategies included: providing reassurance and support (73.8%), listening to the patient (69.2%), providing information (45.2%), ordering further medical tests (47.6%), referring the patient to a specialist (25.4%) and prescribing drugs (48.1%)
Aamland, A., *et al.* (2017). (141)	MUPS, purposive sample of 24 experienced GPs	Focus group interviews. Discussions audiotaped and transcribed. Analysis via systematic text condensation.	A broad range of strategies were helpful in consultations with patients with MUPS, including reviewing previous consultation notes, comprehensively summarizing the patient's medical history, allowing the patient to offload without interruption, and seeking advice from other healthcare professionals. Negotiation of diagnosis interpretations, prioritising symptoms, and honesty about the limits of imaging, occasionally generated tensions, constructive confrontation.

McAndrew, L. M., *et al.* (2018). (123)	MUS	Editorial	Interventions for MUS may be categorized into: 1. Reassurance: explaining that the MUS does not reflect a single medical condition. May lead patients to feel their concerns are being dismissed and that the provider is inexperienced or uncaring 2. Reattribution: attributing the cause of MUS to stress/emotions 3. Collusion: appeasing the patient by prescribing unnecessary care/tests
Sitnikova, K., *et al.* (2018). (142)	MUS, n=77 patients identified through EMR search[5] of RCT[6]	Observational study, quantitative analysis of management strategies categorised according to the Dutch guideline.	Symptom exploration was only present in 3.5% of consultations. The most common treatment strategies were: Medication (24.6%), discussing progress (16.2%), scheduling follow-up (11.8%), vitamins (11.7%), education and explanation (11.2%), giving advice (10.8%), wait and see (9.4%), and 'talk', 'listening ear', and 'encouragement; (2.7%)
Terpstra, T., *et al.* (2019). (145)	MUS, determined by GPs, 39 consultations with 20 purposively sampled GPs.	Thematic content analysis of transcripts of video recorded consultations	GPs provided explanations for MUS in nearly all consultations (36/39). Explanations were generally communicated vaguely, as a possibility and in a patient-specific way. Seven categories of explanation components emerged: 1. Defining symptoms: naming them in layman's terms or medical terminology or redefining them by localizing them to a body part. 2. Stating causality via: i. Factors assumed to keep causing the symptoms, ii. Triggering events such as trauma or inflammation, iii. Mechanistic risk factors and iv. Stating that the cause was unknown (to the GP). 3. Mentioning contributing factors: such as fatigue, worry, or others implicated in aggravating or perpetuating symptoms. 4. Describing mechanisms: often vicious cycle-type mechanisms and linking of definitions to components of symptoms as a mechanism 5. Excluding explanations: excluding alarming disease, mentioning lack of concern about particular conditions. 6. Discussing the severity of symptoms, including prognosis, possible consequences. Minimizing severity and seriousness. 7. Normalizing symptoms, focus on absence of apparent disease.
Stortenbeker, I., *et al.,* (2019). (146)	MUS and MES patients, 18 GPs, 393 consultations	Quantitative comparison of the frequency of implicit markers of uncertainty	GPs were 1.54 times more likely to express uncertainty in MUS vs. MES consultations, particularly during diagnosis and treatment recommendations compared to physical examinations.
Gol, J., *et al.,* (2019). (147)	MUS, 18 GPs, 39 consultations identified by GPs as pertaining to MUS	Qualitative thematic analysis of management strategies in videos and transcripts of consultations	105 management strategies were identified, with six emerging themes: 1. Cognitions and emotions: discussions generally initiated by the GP with vague, impractical instructions communicated as an order, such as "don't worry about…", or "just accept it, leave it be." 2. Interactions with health professionals: generally comprehensive and clear instructions on how to communicate with healthcare professionals. GP explaining their role and willingness to help. 3. Body focus: practical, brief, non-specific symptom management advice mostly resulting from a dialogue or from a direct question of the patient. i.e. home remedies, posture, nutrition. 4. Symptom knowledge: strategies to increase patients' knowledge about their symptoms through use of a diary to gain further insight or provision of informational documents from the GP. 5. Activity level: advice from GP to either stay at the same activity level or do less, maintain a daily rhythm with sufficient rest. 6. External conditions: adjustment strategies for work or home life to manage symptoms, communicated vaguely with pros and cons. Advice on symptom management was often non-specific in terms of content, not practical or operational. GPs communicated this information vaguely, raising doubts about strategies they proposed.
Stortenbeker, I. *et al.* (2020). (46)	MUS in medical settings, varied criteria, n=18 publications.	Systematic review, 18 publications, linguistic and interactional analyses, synthesis according to the	Three dimensions of linguistic and interactional features of consultations: 1. Symptom recognition: discussion of the legitimacy of symptoms and recognition of their severity. Patients claiming legitimacy, using intensified language to indicate severity. Healthcare providers (HCPs) validated patients' experience with diagnostic labels and common

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[5] Electronic medical records (EMRs) were searched for potential participants "who had consulted their GP at least twice in the previous 3 months with one or more complaints from the Robbins list," (143) a list of 23 symptoms associated with functional somatic syndromes. GPs verified that these patients indeed had MUS, and those that met exclusion criteria (presence of a medical or psychological disorder explaining the symptoms, presence of a severe psychiatric disorder, currently receiving psychological treatment for MUS, having poor language skills or handicap that prevented patients from understanding the intervention) were excluded.

[6] Randomized Controlled trial (RCT) called the CIPRUS study, which aims to establish the effectiveness of treatment of undifferentiated somatoform disorder by a mental health nurse practitioner within general practice versus usual care. (144)

	5 in general practice.	principles of meta-ethnography.	syndrome descriptions, providing tangible explanations that are co-constructed with patients. If HCPs do not acknowledge patients' experience of symptoms, patients felt defensive and hopeless 2. Double trouble potential: patients and providers have differing views on symptoms and different knowledge domains. HCP explain MUS with caution through vagueness, mitigation, detached footing and indirect constructions. When conflicting ideas become manifest, patients resist. 3. Negotiation and persuasion regarding acceptable explanations and subsequent psychological treatment. HCP pursue patient acceptance of symptom explanations or treatment recommendations using information gathering strategies. They work towards agreement with patient through persuasive strategies such as a. tailoring explanations, b. framing and subtle and c. action recommendations.

Synthesis of results:

A. Management Strategies Not Related to Communication

Diverse management and treatment strategies were employed in the consultations. Somatic interventions, including prescription, further investigation, or somatic treatment, were repeatedly employed, (50,105,125,134,142) and often proposed by the PCP, rather than the patient. (50,125) Referrals for further consultations were also proposed (105,125,134) as well as scheduling regular follow-up appointments. (134,142)

B. Structure of the Consultation

Seven articles focused primarily on defining the structure of the clinical consultation based on the interaction between patient and physician. (42,43,103,128,138,139,141) In one study that examined consultation types based on the PCP's approach, three types emerged, categorized based on adherence to a biomedical model of the consultation and consideration for the patient's perspectives. (138) The three types were identified as: 1. searching for a disease, in which the PCP uses medical investigations and thorough assessments in an attempt to localise the pathology, 2. going by the routine, in which the PCP examines and attempts to diagnose the patient, taking a pragmatic approach and addressing primarily the physical side of the problem, rarely acknowledging cues from the patient. Both of these were largely biomedical and did not allow for the patient's perspective to be heard. The third type, 3. 'following various paths' was characterized by consideration of physical, psychological and social explanations for the symptoms through a dialogue with the patient, and negotiating towards a shared understanding of the meaning of the symptoms. (138) A study that reviewed explanation sequences categorized the consultation based on dialogue type and found that 38% could be categorized as 'deliberation,' a structure in which the PCP and the patient both contribute ideas and work towards a mutually acceptable explanation. The remaining three dialogue types identified:

lecture, storytelling, and contest, were primarily PCP-led or characterized by a contest over the dialogic space, (139) with minimal consideration of personal details of the patient, though contest in particular was characterized by blocking and counterstatements from both parties.

The negotiation of explanations within the consultation takes various forms, with degrees of agreement and alliance between PCP and patient. Salmon (103) defined three typologies of the consultation; contest, in which patients seek legitimacy for their problems and PCPs provide simple reassurance that does not engage with their concerns; collusion, in which PCPs simply acquiesce to patient's tentative suggestions of explanations or treatment strategies; and collaboration, in which both parties strive towards common ground and shared understanding. (103) Another study examined PCP responses to patient symptom presentations and classified them according to whether the PCP ignored the symptoms, clues or concerns expressed by the patient, responded to the patient without exploring symptoms, clues or concerns, or explored the symptoms clues and concerns by asking more about the patient's situation, investigating the patient's underlying worry, or gathering more information about the medical nature of the problem. (128) While exploring the symptoms, clues, and concerns was the most common category, most of these explorations did not engage with the underlying concerns of the patients. In a comparison of patient-centered communication between consultations pertaining to MUS versus medically explained symptoms, it was found that in the case of MUS, physicians yielded significantly lower scores on a metric of patient-centered communication in consultations with MUS compared to in those pertaining to medically explained symptoms. (43)

The dynamics of the consultation after the PCP experienced difficulty in clarifying the link between the somatic experiences and psychosocial circumstances of the patient were characterized by either mutual alliance by going about ritual care routines to preserve a good relationship, ambivalent alliance in which the PCP resented the ritual care they continued to provide, and non-alliance, on the rare occasions that the PCP cut off all reasons for consultation and indicated this by communicating negative findings, taking a cool objectifying gaze, and informing the patient that they should not consult with issues of this nature. (42) These three structures of alliance within the consultations reflect the challenges faced by both parties in reaching an agreement on the structure of primary care for patients with MUS. In a focus group study in which GPs were asked to identify helpful strategies for managing patients with MUS, these included reviewing the previous consultation notes and summarizing the patient's medical history, allowing the patient to 'get it all off their chest,' honesty about the limits of medicine, and negotiation and constructive confrontation regarding diagnosis and treatment. (141) In reviewing the consultation dynamics, the approaches in which the physician dominates the dialogic space and a narrow biomedical perspective is emphasized appear to be fraught with unconstructive tension and difficulties in reaching a shared understanding of the symptoms. This being said, criticism in the consultation is not necessarily an indicator of discord. In a study of the audio-recorded consultations of 249 patients with 34 GPs, criticism or contradiction of a patient's actions or statements by physicians was recorded in 27.1% of consultations and was positively associated with the GPs belief that they shared responsibility with the patient as well as the GPs positive model of themselves. Criticism was inversely associated with GPs belief that patients' feelings were legitimate business for consultation. (126) Thus, it appears that criticism by the PCP may reflect their belief in the legitimacy of the suffering of patients with MUS and their sense of responsibility to care for their suffering.

C. Explanations and Normalisations

While the nature of the available data does not permit for a quantitative review of the responses PCPs offer to patients' symptom presentations, it is worth noting that normalisations are the most frequently reported response. (42,50,80,118,145) Normalisation may be defined as statements indicating the likely absence of serious disease, that symptoms are likely to be benign or self-limiting, and are within a common acceptable range of experience, therefore not requiring healthcare intervention. (80) Ring and colleagues found that half of GPs employed a normalisation strategy by indicating the absence of physical disease, while two thirds provided explanations other than physical disease. (50) Thus, normalisation may include discussion of potential explanations that display the benign nature of the symptoms.

Dowrick and colleagues identified three types of normalisations based on their effects: 1. Normalisation without explanation, which includes either the dismissal of the presence of disease, appeal to the authority of a negative test result, or rudimentary reassurance, 2. Normalisation with ineffective explanation, which attempts to imply that healthcare intervention would be minimal or unnecessary through an explanation of the symptoms with a tangible physical mechanism that is not linked to patient concerns, and 3. Normalisation with effective explanation, in which a tangible mechanism emerged from discussion with the patient, which may include links between psychosocial and physical factors. (80) Nunes and Ventura found that normalisation with ineffective explanation may be effective if a trusting therapeutic relationship was already established, but that without this relationship, it was associated with the lowest level of patient satisfaction. (118)

Similar approaches to normalisation of symptoms included expressing to patients that there is no disease and that nothing is wrong, (42) excluding alarming disease and mentioning lack of concern about particular conditions, focusing on the absence of apparent disease and normalising symptoms (145) and providing vague instructions to patients such as "don't worry about [it]" or "just accept it, leave it be…" (147) PCPs also attempted to reassure patients regarding their symptoms by explaining that MUS do not reflect a single medical condition (123) or providing general reassurance (135) which did not engage with patients' concerns.

Attempts at explaining the symptoms often did not incorporate patients' beliefs and concerns, even when these were discussed in the consultation. (135) Metaphors were employed to provide insight into potential interactions between symptoms and psychosocial life, (42) and reattribution strategies included attributing the cause of MUS to stress or emotions. (123) In a 2017 study by Morton and colleagues, explanations for symptoms were categorized based on who was given agency for the symptoms and the emphasis of the symptom explanations. (140) Explanations were labelled rational adaptive if they described symptoms in terms of biological or psychosocial processes that caused or perpetuated the symptoms, giving the patient agency over the process; automatic adaptive if they linked an involuntary, typically physiological stimulus to the symptoms; and complex if no clear link between a stimulus and its consequences was offered, locating the symptoms in the intricate interplay of different body systems, giving agency to these unknowable, complex systems. (140) Similarly, 'vicious-cycle' type explanations were offered by the GPs in a 2019 paper by Terpstra and colleagues, (145) who found that explanations that described mechanisms often included mention of vicious cycles. They also identified explanations that consisted of defining the symptoms by naming them in layman's terms, or attributing causality to various factors that triggered or perpetuated symptoms, such as trauma, fatigue, or worry. Generally, symptom explanations were not specific to the patient, nor were they oriented around the patient's concerns, even when these were discussed in the consultation.

D. Patient Responses

Few of the studies that examined patient's responses to these explanations reported that patients felt reassured or otherwise felt positively about the explanations they were offered. Dowrick and colleagues found that the two non-specific normalisation types identified did not reassure the patients, who responded with more robust presentation of their symptoms and provided external authority for their symptoms. When explanations accompanying normalisations were effective, discussion of psychological or social problems could follow. (80) A 2007 study by Salmon also found that normalisation and simple reassurance prompted patients to intensify their accounts of illness, (103) and both studies found that this might eventually lead GPs to proposing somatic intervention. (80,103) Patients valued listening and reassurance and advice from their clinician, but non-specific reassurance and normalisation without explanation left patients without existing trust in their clinician unsatisfied. (118)

Two articles examined the ways patients demonstrated their acceptance or rejection of proposed explanations. (136,139) They found that patient acceptance of explanation included explicit acknowledgment of the explanation as helpful and expression of the possibility of adopting ideas it contained, while rejection was characterized by explicit disagreement or provision of an unarguable counterfactual, such as stating that a particular explanation was impossible given what the patient was experiencing. (139) In some consultations, no definitive conclusion was reached, and patients responded without directly engaging with the explanation they were provided. (136,139)

Discussion

In reviewing the management strategies employed, we see the manifestation of the finding that physicians, not patients, frequently propose somatic intervention, (50,125) including further investigations, treatments and prescriptions. (50,105,125,134,142) This is despite the available evidence, including two Cochrane reviews, indicating that the evidence for physical treatment is absent and the role of pharmacotherapy is very limited. (57,148,149) Guidelines for the management of MUS state that doctor-patient communication is key, and emphasize the importance of exploring patients' ideas and concerns, discussing their expectations, and providing explanations that they find acceptable. (148) This is not what was found in this review of the communication regarding MUS, which largely neglected patients' ideas and concerns, centering the consultation around the biomedical search for disease while rarely acknowledging clues from the patient, (138) and minimally considering the personal details of the patient in consultation dialogue. (139) While these guidelines emphasize the importance of discussing patients expectations and providing explanations they find acceptable, (148) most of the attempts and reassurance or explanations regarding symptoms were non-specific (135) focusing on the absence of disease (145) and failing to engage with patients' concerns or their explanatory models. Vague instructions were offered to patients in an attempt to reassure them, (147) and patients' concerns were largely not engaged with. While some explanations were co-constructed with patients and led to discussion of psychological or social problems patients faced, (80) most were simple, non-specific and unsatisfying to patients. (118)

PCPs used a variety of approaches to explaining symptoms, such as metaphors to provide insight into potential interactions between symptoms and psychosocial life (42) and reattribution techniques that have been found to improve PCPs' skills and attitudes in consultations with MUS patients but have not been linked to improved patient outcomes. (57) They attempted to explain symptoms through mechanisms such as vicious cycles and the intricate interplay of body systems, with explanations that placed agency over the symptoms within the patient or in bodily functions that were outside of their control. (140) It is not clear, however, that any of these explanations were based on concerns expressed by patients or explanatory models that patients had considered. While PCPs may make good faith attempts to normalise the patient's experience of symptoms, reassure them, and offer care, they also appear to be at a loss, justifying offers of somatic intervention as a response to perceived patient pressure, (51,125) even when PCPs are uncertain about the appropriateness of somatic interventions and patients did not express a desire for these interventions. Efforts to respond to the needs of patients with MUS demonstrate a failure to understand and engage with what these needs are, resulting in care that patients find unsatisfactory, explanations that do not address their concerns, and frustration in both parties.

The limitations of this review are largely related to the selected study populations. Most had small sample sizes and a low proportion of patients recruited consenting to participate. This may be related to the recording of the consultations, the accessibility of the interviews in which patients would have to participate, or the characteristics of MUS patients that made them more likely to be selected by their PCP for these studies. Similarly, the PCPs participating in these studies are often self-selected, favouring those who may be more concerned about MUS and about providing appropriate care to patients with MUS. Some of the studies included in this review were related to trials of interventions to improve communication regarding MUS, (136,139,140) and as a result, communication strategies reported do not reflect those that would occur organically in primary care not oriented around MUS. Nonetheless, these approaches did not appear to be meaningfully more successful at communication with patients with MUS, nor did they truly engage with the concerns of individual patients.

Other studies are limited by the use of self-report and the recall of information from several months prior, as well as contamination of the patients' ideas and expectations related to their long-term therapeutic relationship with their GP. While there is concern that video-recording and audio-recording may modify the communication in the consultation, it has been recommended as the best method for researching this, (150) and there is little evidence of influence on the behaviour of physicians or patients, though it may impact the characteristics of physicians and patients who agree to participate. (151) Some studies attempted to mitigate the effects of this bias by having the physicians and patients unaware of the subject of the study to more closely reflect the reality of daily practice (135) or by extracting data from electronic medical records post-hoc, (142) though this approach is victim to the limitations of the information documented by physicians, which may not accurately represent the consultation, and may emphasize the more tangible (somatic) interventions while limiting or neglecting to document the particulars of communication.

The physician-centric nature of the available data is perpetuated through the categorizations of explanations and normalisations, which may be considered physician-centred. (42) While the inclusion of reviews in this critical interpretive review allowed for reinforcement of the typologies of explanations, it also embedded the constructs defined by previous researchers as ways of categorizing explanations, without providing evidence on how patients would categorize these explanations. The perspective of patients on normalizations, reassurance, and explanations they are offered, as well as the structure of the clinical consultations is limited to how satisfied they are with the interactions or information provided. Patients' perspectives on the information they are provided, not just how they perceive it but how they conceptualize it more broadly, is entirely lacking, and merits exploration. Future research should examine more closely these interactions between patients and physicians and focus on the co-creation of acceptable explanations for symptoms, as well as the dialogic approaches that allow for this negotiation to occur constructively.

Final Discussion and Conclusion

This literature review explores responses to three questions pertaining to the communication about medically unexplained symptoms in primary care: 1. What are the beliefs of patients with MUS regarding the nature of their symptoms? 2. How do patients express their beliefs and desires for care in primary care? 3. How do PCPs communicate with patients and respond to their requests and expressed needs? Building on the conceptual issues outlined in Chapter 1, the responses to these questions inform a discussion of the ethical issues in the care for patients with MUS, focusing on the challenges of communication.

The findings of this literature review reveal that patients with MUS have diverse and complex explanatory models, including a number of ideas about how stress, trauma, and other psychosocial factors contribute to symptom generation and perpetuation, which they readily express to their physician. Patients may be eager to discuss these ideas, as the literature responding to the second question revealed that patients with MUS express numerous concerns, including psychological, social and biological perspectives on their symptoms, which are clues to their expectations from their PCP. In addition to implicit clues, patients make explicit requests for care and may identify their goals for care. These goals overwhelmingly included expectations of explanations for their symptoms and identification of their cause, (49,116,118–120,122,124,126,132) attentive listening and honest communication, (36,118,119,131,132) and empathy, support and understanding of their suffering. (33,65,118,120,122,124,126,131,132) Further, patients were found to expect help with coping more commonly than a cure or complete alleviation of their symptoms. (122) While some patients did expect somatic intervention, including appropriate investigation of their symptoms, it is unreasonable to draw from this the commonly held conclusion that patients make unreasonable requests for somatic intervention and investigation, a belief that has already been found to not be supported by the evidence; physicians are often the ones to offer somatic intervention, (50,125) justifying these offers as a response to perceived patient pressure. (51,125)

In reviewing the evidence collected in response to the first two questions, it becomes clear that patients have complex beliefs about their symptoms and typically have reasonable expectations from their physicians. While there are likely numerous exceptions to this, patients with symptoms that are medically explained may also have beliefs perceived to be irrational or make requests for care that may be unreasonable. Further, the narratives that patients have poor insight into their symptoms and psychological state and make unreasonable requests for somatic intervention are not supported, which raises further questions about what makes the MUS consultation so challenging. Patients have several complex and fluid explanatory models for their symptoms, which reflects an effort to make sense of their illness, to find meaning in their suffering. Considering several explanations, while these may not all necessarily be physiologically or mechanistically plausible, may reflect a relatively scientific thought process wherein these explanations may be informally tested by patients to determine how or whether they could be contributing to their symptoms. Nuanced idioms of distress may be challenging to explore in the biomedical consultation; however, these are likely to be rich with information that can guide the physician and patient towards an understanding of contributing factors to patients' symptoms.

Not only is this consistent with a PCC approach, which prioritizes exploring the illness experience, understanding the whole person, and finding common ground as central tenets of the method, (19) it also may help physicians make sense of patients' symptoms and provide them with the explanations they so desire. In fact, patients' explanatory models may generally be quite similar to hypothetical mechanisms of MUS generation and perpetuation, reflecting similar ideas about psychosocial stressors and personal and cognitive characteristics contributing to patients' symptoms. (76,77) It is common for physicians to find patients with MUS challenging and frustrating (41) and may consider their symptoms invalid, (51) contributing to less patient-centered consultations with these patients than with others. (43) Pre-existing biases against patients with MUS and ideas about their expectations may preclude constructive communication in the consultation and contribute to many of the challenges of understanding the patients' suffering and appreciating its legitimacy. It is unclear whether these frustrations and challenges arise prior to the determination that symptoms are medically unexplained, potentially impacting that conclusion, or after initial investigations fail to reveal a cause for the symptoms, suggesting to some clinicians that the patient may be feigning illness or somehow at fault, and contributing to vicious cycles of fighting for medical legitimacy and symptom exacerbation.

Guidelines for the management of MUS state that doctor-patient communication is key, and emphasize the importance of exploring patients' ideas and concerns, discussing their expectations, and providing explanations that they find acceptable. (148) This may not be as difficult as some physicians believe, if they explore the explanatory models and beliefs of patients, which, as revealed through this literature review, are generally reasonable and consistent with a patient-centered approach to care. This additionally would simplify and improve the provision of explanations for symptoms, as many of those offered by physicians fail to account for patients' ideas about their illness and their own explanations. Though resistance to explore these may be related to beliefs that they will be unreasonable or lead to conflict in the consultation, this is not supported by the evidence included in this review.

Primary care consultations with patients with MUS may be less patient-centered than with patients with medically explained symptoms, (43) despite exploration of illness experience being a fundamental tenet of patient-centered care, and the particular need to explore this in the absence of medical explanation for patients' symptoms. This critical interpretive review of communication regarding MUS in the primary care consultation found that across a large volume of literature on the topic, patients have explanatory models that are relatively consistent with existing hypothetical models, that their expectations are generally reasonable, and that approaches that PCPs take to communicating about the symptoms often fail to account (or even acknowledge) these perspectives of patients. The guidelines for caring for patients with MUS (57,148,152) are consistent with the methods of patient-centered medicine, which is accepted as valuable, important, and beneficial to patients. (111) Considering the findings of this literature review that demonstrate the importance of communication about symptoms and the reasonable ideas and expectations patients have about their symptoms and their medical care, it is both crucial and not preposterous to conclude that a more patient-centered approach to communication would be beneficial. Inviting the patient’s perspective on their illness through open-ended questions, and engaging with these through active and reflective listening (elements of patient-centered communication (19)) and considering these in their care is essential and invaluable in reimagining care for MUS in a way that is ethical, responsive to patients’ needs, and that prioritises their health and alleviating their illness burden and suffering.

Chapter 3: Ethically Evaluating Primary Care Communication about Medically Unexplained Symptoms: Epistemic Injustice & Other Harms

Introduction

The “primitive, experiential and existential illness phenomenon” (153) is a fundamentally private, subjective experience, accessible to others only indirectly through the affected individual’s reports. Virginia Woolf, in her essay *On Being Ill*, describes the intervention of the body in illness, the changes and disruption felt, the “daily drama of the body” for which “there is no record.” (154) The experience of symptoms, and the phenomenon of illness more broadly, only become tangible when the ill person’s suffering is expressed, or [re]created and recorded through language, illness narratives that convey the experience to the outsider. The process of transformation, though it indelibly alters and diverges from the experience of illness itself, is essential to biomedicine, guiding the clinical encounter, particularly the diagnostic and treatment processes, to allow the clinician to address the illness experience, generally through the treatment of disease. The clinicopathological process consists of ordering diagnostic tests based on a reasonable range of possibilities determined based on the patient’s account of their illness and their physical examination, in order to classify and characterize symptoms according to a disease-based framework, (30,155,156) followed by a hypothetico-deductive reasoning approach to making a diagnosis, through asking questions and reviewing the information obtained in the patient’s illness history to strengthen or disprove the tentative diagnosis. (131)

Illnesses may become reified through this clinicopathological process; collecting evidence from the patient’s illness testimony, typically guided by the clinician’s questions, the physical examination and subsequent diagnostic tests. With MUS, this reification fails; the patient’s symptoms cannot be clinicopathologically correlated with known disease constructs. By definition, MUS[7] cannot be translated into a form manageable within biomedicine, which may result in doubt surrounding the legitimacy of the patient’s illness. MUS represent an intractable

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[7] MUS is commonly used to denote psychogenic symptoms, symptoms that are unexplained medically and have primarily psychosocial causes, (28,48) an inappropriate and confounding use of the term. Throughout this thesis, MUS is used to refer to persistent physical symptoms experienced by individuals, for which they seek medical attention, but for which no clear pathophysiological process or organic change can be identified to explain the symptoms, which also cannot be attributed to psychoactive drug use. (23–25)

challenge for biomedicine; raising epistemic problems by virtue of the fact that they cannot be adequately attributed to an underlying pathology, and ontological problems given the way they challenge traditional biomedical models of explanation that centre objectifiable pathological abnormalities and do not adequately account for the patient's illness. The failure of the diagnostic process is likely to be a major contributor to physicians' frustration with patients with MUS. In fact, PCPs have been found to struggle with their learnt biomedical concepts of disease, even with added psychosocial approaches, and the opposition of these to personal illness and symptom experiences and explanatory models of patients. (28) PCPs struggle with epistemological incongruence between known disease models and the reality of the suffering patient, experiencing incongruences at a relational level, as well as difficulties at an illness conceptual level. (28) It is well documented that PCPs find patients with MUS frustrating, (41–43) yet many feel that primary care is the appropriate setting for the management of MUS. (40)

Further exacerbating the challenge of addressing MUS is that without clinicopathological correlation for the patient's symptoms, the physician lacks the professional authority that grants them access to patient's illness. They do not have recourse to management approaches or treatment modalities to guide their care, and lack of guidelines and insufficient training in the management of patients with MUS have been cited as primary challenges that PCPs face in caring for these patients. (157)

The biopsychosocial model[8] has attempted to subvert this biomedical reductionism, but remains fundamentally limited, failing to address many of the shortcomings of biomedicine, not adequately reconciling the constructed silos of the biological, psychological, and social realms, remaining essentially mechanistic and dualistic, (17) and not offering systematic and actionable methods to investigate and integrate the biological, psychological and social in clinical practice. (17,18)

This chapter builds on the evidence and arguments in Chapters 1 and 2 to analyze the ethical issues raised by PCPs' approaches to communication about MUS in primary care, drawing from patient-centered clinical methods, PCP's duties of care, and the phenomenology of illness.

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[8] The biopsychosocial model, put forth by George Engel in 1977, was an effort to broaden the medical perspective and provide a more holistic regard on illness, integrating the biological, psychological, and social spheres of the individual's life and understanding how they shape their illness experience. (15)

This analysis is conducted in four main parts; first, A) making a case for the need for an ethical inquiry into communication surrounding medically unexplained symptoms, then B) outlining the standards, guidelines, normative and ethical considerations against which current primary care communication with MUS patients will be compared. Following this, it will be argued in part C) that patients with MUS suffer from a salient, multifactorial burden of epistemic injustice, owing to a number of interacting elements that contribute to their illness experience being discredited. In part D) the ways in which epistemic injustice contribute to a variety of harms in the care for patients with MUS will be explored. Throughout this examination, the duties of care of PCPs, and their responsibilities in communication, including honesty, effective listening, transparency, and informed consent will be referenced, as well as interrogating how these harms bear on matters of justice and access to care. This analysis, alongside the first two chapters, patient-centered clinical methods, and existing guidelines for the care for patients with MUS will inform the fourth, concluding chapter, which endeavours to outline more ethical, effective, and evidence-based methods to communicate with and care for patients with MUS.

Part A: Why does this merit ethical investigation?

Richard A. A. Kanaan expresses that "[t]he strongest evidence that there is a bioethical problem in the realm of medically unexplained symptoms (MUS) is the presence of angry patients, however few there are." (158) The frustration of both patients and physicians, in addition to the evidence for the psychological distress, lower ratings of the quality of GP care, and functional impairment of patients with persistent medically unexplained physical symptoms (69) and the significantly lower health-related quality of life compared to patients with medically explained symptoms (159) is sufficient to ascertain that care for patients with MUS is lacking and challenging for all parties in question.

While practice guidelines have attempted to address these challenges and shortcomings of the care for MUS patients, their evidence base is limited and there are several barriers, such as uncertainty regarding how to explain symptoms constructively, that prevent the recommendations from being taken up into practice. (148) Further, the guidelines do little more than address the difficulties superficially, without addressing the underlying issues of disbelief of patients, power and authority, and physicians' contributions to iatrogenesis. To be sure, this analysis does not intend to depict PCPs caring for patients with MUS as malicious or deliberately neglectful of the patient's illness experience, worries and concerns. It is recognized that this is overwhelmingly not the case, and that many of the difficulties PCPs face in attending to the needs of these patients lie at the intersection of structural barriers, such as limited time and resources, and the limitations of medical training that is fundamentally based on a biomedical, disease-centric model. This ethical examination of primary care communication about MUS is necessitated by the belief that the difficulties in the clinical encounter run deeper than those addressed through clinical guidelines, and that addressing these barriers requires an approach that recognizes the primacy and inherent value of patients' testimony of their illness experience.

Patients with MUS suffer from a triple threat to their legitimacy within biomedicine, in which the ability to clinicopathologically correlate symptoms with a known disease is central. First, when investigations fail to reveal an explanatory pathology that would adequately explain their symptoms, their legitimacy as patients may be questioned. This is to say that the absence of evidence for a biomedical cause for their suffering is taken to indicate the absence of cause altogether, and thus that the patient is not genuinely suffering. The patient may then be considered to be feigning their illness, not truly ill, or may be perceived to be suffering in a way that is invalid or misplaced, such as the common belief that patients with MUS are making an epistemic error, misinterpreting psychological distress as physical phenomena (20) which is seen as regressive. (86) This second issue undermines their immutable expertise over their own experience. Third, in response to this doubt and the threat to the legitimacy of their suffering, or pre-empting this altogether, patients may work to become knowledgeable on their symptoms, making inexpert efforts to interpret them in ways that appear to be mechanistically and biomedically plausible, attempting to patch together an explanation based on their experience and their understanding of physiology. Their attempts to simplify their hypothetical explanations in the primary care encounter and other judgements patients make about how and what to present to their PCP (130) may demonstrate this. Physicians may be frustrated by patients' attempts to use knowledge that is seen as outside of their scope and may resist their efforts to communicate biomedically. Patients with MUS have the primacy of their suffering disbelieved, may not be trusted to appropriately translate and convey their illness experience, and may be further resented or viewed contemptuously when their attempts to make sense of their illness biomedically or their work to be perceived as legitimately suffering render them conspicuous.

These three related threats to the authority of patients to appropriately and accurately experience, interpret, and express their suffering speak to the notion of epistemic injustice, as defined by Miranda Fricker, (160) the harm done to a person in their capacity as an epistemic subject by undermining their ability to engage in practices such as testifying or interpreting their experiences. (160) This chapter argues that patients with MUS suffer from a distinct and noteworthy form of epistemic injustice due to the intersecting issues of i. The absence of biomedical evidence to support their illness testimony, ii. The method of conveying their illness testimony, which may be apt to be written off as incoherent, irrational, or too emotional, especially in the absence of supporting evidence for their suffering, iii. The belief that patients with MUS are suffering from psychiatric distress which they are iv. Believed to be misinterpreting as physical symptoms, v. The need of MUS patients to prove they are ill, rendering them particularly conspicuous and vi. The groups to which those with MUS disproportionately belong. Building upon this, an exploration of the ways in which these layered injustices manifest themselves concretely in practice, resulting in a range of important harms, will be conducted.

There has been limited work to uncover the ethical quandaries raised by care for patients with MUS; those that results from care that is unduly focused on disease and neglects the patient’s illness experience, those that rely on and perpetuate power imbalances between physician and patient, and those that result in iatrogenic, harmful processes that entrench patients’ focus on their symptoms. Guidelines for caring for patients with MUS address the broad issues of dissatisfaction and communication challenges, without addressing the underlying doubt about patients’ legitimacy, communication difficulties, and relational dissonance. This ethical examination addresses these issues and the clinical and conceptual challenges stemming from a lack of clarity about what comprises appropriate care for MUS.

Part B: Standards, Guidelines, Normative and Ethical Considerations Guiding this Analysis

The arguments contained in this chapter are based on the notion that the patient has the ultimate authority over their experience of illness; a foundation upon which Patient-centered care (PCC) was built. A patient-centered clinical method shifts the perspectives fundamental to biomedicine; questioning the entrenched paternalistic power dynamics in the clinical encounter, the idea that the physician is in charge and holds power over the passive patient, and argues that maintaining an exclusively objective stance towards patients produces an unacceptable insensitivity to human suffering, (19) which is not conducive to care that is responsive to the needs of patients, especially those which are not addressed through the treatment of disease. To accomplish this, PCC offers conceptual frameworks to integrate disease, illness experience, and health to synthesize an integrated understanding that is unique to each patient. Through four interactive components of the patient-centered clinical method, the relationship between patient and physician can prioritize the experiential primacy of the patient's illness experience and their ultimate authority over this, while offering approaches to elicit this experience in practice. The four components, alongside their sub-components, slightly adapted for brevity from Stewart et al. are as follows: 1. Exploring Health, Disease, and the Illness Experience; through an understanding of the patients unique perceptions and experience of health, the dimensions of their illness experience, including their feelings, disease, effects on function and expectations, and their history, physical exam, and lab results. 2. Understanding the Whole Person; including their life history, their proximal context and social setting, and the distal context of their community and culture. 3. Finding Common Ground between physician and patient; exploring priorities and problems, goals of treatment and care, and the roles of patient and doctor, and 4. Enhancing the Patient-Clinician Relationship through compassion and empathy, healing and hope, and an understanding of power. (19) This method should be integrated with an evidence-based medicine (EBM) approach, in which EBM assists the physician in determining what elements are appropriate to inform their perspective on the patient's illness when working towards finding common ground with the patient, a key to successful clinical outcome. (19)

Stewart et al. provide methods and examples of the application of PCC in practice in their book, *Patient-Centered Medicine, Transforming the Clinical Method*. For the ethical analysis in question, it is sufficient to understand this conceptually and note the primacy of the patient's experience of illness in this framework, which needn't be seen as threatening nor undermining the physician's biomedical expertise nor their extensive training. Early attempts to adopt this framework in the care for patients with MUS have had equivocal results, (161,162) though they have attempted to operationalize PCC in an effort to study it rigorously, rendering it no longer truly patient-centered. A PCC approach has been suggested as a means of treating patients with MUS in primary care (163) including through a cognitive behavioural model, with some success at helping the patient construct a clearer narrative of their symptoms and their concerns, (164) which pairs well with the phenomenological patient toolkit conceptualized by Havi Carel. (165) Operationalizing PCC to a set of specific rules for clinical practice effectively eliminates its patient-centeredness. Rather, the approach must be taken holistically as a guiding philosophy, a framework through which the experiential primacy of the patient's illness can be understood as complimenting, not compromising biomedical evidence or the physician's expertise.

Phenomenology also places the patient's experience of the illness phenomena at the fore, using the patient's account of their symptoms as the disclosure of how the individual constitutes the meaning of their experience, a meaning that is grounded in lived experience, and which is fundamentally distinct from the meaning the physician can construct. (166) S. Kay Toombs, in her work on the phenomenological approach to medicine, highlights the need for the physician to recognize the essential nature of the disruption of the lived body experienced by the patient, and how this phenomenon is fundamentally distinct from the disease state constituted by the physician. Understanding this, the physician can care for patients with MUS in a way that does not undermine nor elide the patient's illness experience. A phenomenological approach to MUS avoids the impossible task of making the patient's illness fit neatly into a disease construct. In order to fully understand illness, it must be studied as a lived experience, exploring its existential, ethical and social dimensions. (167) Phenomenology does not seek definitive causal explanations for empirical phenomena, it does not posit phenomenal data as objectively real or absolute. (167) Rather, in the phenomenological approach defined by Husserl, it seeks to generate transcendental data on the conditions of possibility of mental acts. (168) Considering that much of physician's task is to listen to the patients' account of their illness in order to generate plausible hypothetical explanations for their suffering, employing a phenomenological approach within a patient-centered method appears to be well-suited to this goal.

To make explicit some of the ethical issues raised by care that does not meet these criteria, codes of ethics and physician codes of conduct are referenced, including the Canadian

Medical Association (CMA) Code of Ethics (169) and ethical principles in family medicine, including the value of the patient-physician relationship, fundamental to primary care. (170) The analysis of epistemic injustice is based on the notion as defined by Fricker, (160) Havi Carel's work on the phenomenology of illness, (167) and examinations of relevant forms of epistemic injustice.

Part C: Medically Unexplained Symptoms and the Intersecting Elements of Epistemic Injustice

I cannot count the number of times that I have heard[9] a physician comment that a given patient–often one with vague patterns of numbness, or chronic abdominal pain with an as-yet unidentified cause–does not have 'real' symptoms. This may be posed to a trainee in the form of a question, to ascertain whether they can recognize the difference between non-specific generalized numbness, for example, that is unlikely to represent an underlying identifiable neurological pathology, and specific patterns of numbness that could correspond to a worrisome disease, such as Multiple Sclerosis or a lesion of the spinal cord. While generally rhetorical or meant for teaching and recognized by physicians as colloquialisms and commentary on the presence or absence of disease–not of symptoms or pain, these statements are important. First, they speak to the physician's necessary ability and authority to recognize and make meaning of patterns of symptoms, distinguishing those that are likely to represent an underlying pathology from those that are not. It is this expertise, made up of a remarkable breadth and depth of empirical knowledge and a honed clinical acumen, that allows them to effectively investigate, identify, diagnose, and treat disease. Second, they represent the particular epistemic authority and privilege of the physician in the clinical encounter. Their expertise and understanding of how to translate the patient's illness testimony into a differential diagnosis that leads to investigations and often eventually, a diagnosis, allows them to determine what is important and what is not, what is true, and what is not, and what is valuable and what is not in the clinical consultation.

The authority to define what is valid and valuable in the clinical consultation reflects the epistemic privilege accorded to physicians by virtue of their training, expertise, and the impersonal, empirical nature of their knowledge, which Carel argues are reinforced by contemporary healthcare practice which privileges "certain styles of articulating testimonies,

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[9] While working for several years as a medical scribe in an emergency department, witnessing interactions between patients and physicians as well as all those that occur between staff.

forms of evidence, ways of presenting and sharing knowledge," (167). This contributes to the epistemic injustice experienced by patients, or the harm done to a person in their capacity as an epistemic subject by undermining their ability to engage in practices such as testifying or interpreting their experiences. (160) While patients have the intimate knowledge of what it is to live their particular experience of illness, physicians maintain their epistemic privilege by virtue of their scientific, medical knowledge and clinical expertise, the power afforded by traditionally paternalistic patient-physician relationships, and additional social and procedural privileges as gatekeepers of the clinical setting and often as members of privileged groups and institutions.

While ill persons suffer epistemic injustice, suffering from unwarranted disbelief or dismissiveness and decreased credibility in their ability to know, understand, interpret, and testify on their experience, (160,167) patients with MUS are especially subjected to this injustice. They may suffer additional burdens of testimonial injustice, the presumptive attribution of "cognitive unreliability and emotional instability that downgrade the credibility of [ill persons'] testimonies" (171) and hermeneutical injustice, given that the experience of illness is difficult to communicate and make sense of, (172) and particularly so when it is medically unexplained.

In MUS, testimonial injustice is entrenched, as patients' testimonies of their illness are used to dismiss them, or attribute them with symptom labels that carry with them implications of unreliability and instability. Patients with MUS are especially subjected to epistemic injustice owing to a number of compounding and intersecting factors: i. the absence of biomedical evidence to support their illness testimony, ii. their approaches to communicating and expressing their illness experience, iii. the belief that patients with MUS are suffering from psychiatric distress and that iv. they are misinterpreting this psychiatric distress as physical symptoms, v. the perceived conspicuousness of patients with MUS who must work to prove they are ill and vi. the groups to which those with MUS disproportionately belong.

i. The absence of biomedical evidence to support the illness testimony

Disease is the phenomenological and conceptual centre of biomedicine, (153) and illness is seen as necessarily secondary to disease. With MUS, illness exists in the absence of identifiable disease, strengthening the value of objective evidence over the subjective patient report. (81) The patient's knowledge of their experience is undermined by the absence of evidence for a cause, which may be expressed by the physician as an objectifiable, unquestionable truth, such as through the physician's expression that the symptoms are not of significant concern given the absence of physical disease, (50,145) often with appeal to the authority of negative test results. (80) Normalizations may go so far as to express that the lack of identified pathology is evidence of a lack of pathology, and as though the physician has put to rest the question of biological disease. (48) This approach conflates the absence of evidence for an underlying pathology with the false assumption that the symptoms have no cause.

These strategies employed by physicians to convey the unexplained nature of the symptoms rely in their privilege as holders of biomedical knowledge, as well as the power they have to direct the clinical encounter, dictating when it is over, or when the question of biomedical disease has been put to rest. The patient's testimony of their illness may still be believed, but it is dismissed as less important than the absence of identifiable biomedical cause for the symptoms, despite the fact that the experience of illness is unfalsifiable and undeniable, while the absence of cause for symptoms is impossible to prove. First-person accounts of illness have often been ignored or downplayed, and physicians may see these and the patients conveying them as "inconveniently subjective object[s]," (173) and may only begin to take these accounts seriously when the illness is found to be caused by serious disease. When disease cannot be identified, the illness cannot be corroborated by the presence of a pathology. What might otherwise be a case of epistemic injustice in the prioritization of disease and objective evidence over the patient's illness can turn out to be a more severe case, in which the absence of evidence of disease is taken to minimize illness further, or even negate it altogether.

ii. Approaches that patients with MUS use to communicate and express their symptoms

The minimization or even the negation of the illness testimony may be exacerbated by the means by which patients with MUS communicate about their symptoms. The illness narratives of patients with MUS may be seen as incoherent from the outset, when they do not immediately appear to be consistent with known symptom patterns for common diseases. Physicians have been known to complain that patients' speech is full of irrelevant information, and express that listening for medically relevant information precludes listening to other information patients express. (171) MUS patients might be prone to having illness narratives that are seen as particularly irrelevant, confused, or inconvenient, owing to the fact that their symptom patterns are not seen as logically coherent, and that these narratives might be imbued with patients' attempts at making sense of their symptoms in the absence of a biomedical explanation. Premature interruptions of patients has been argued to be evidence of a tacit assumption about the capacities of patients to provide relevant information in healthcare contexts. (174) Their inexpert attempts at making sense of their illness biomedically may be seen as both a (potentially threatening) overstep outside of their scope of knowledge and as laughable, illogical reasoning to an already frustrated or rushed physician. Physicians, known to be frustrated by patients with MUS, (41–43) have been found to experience problems of control in MUS consultations, feeling as though they threaten their authority and cause them to lose their power to direct and control the course of events. (51) Interrupting, redirecting, and guiding the narratives of MUS patients is one way that physicians may preserve their power and privilege in the consultation while undermining the relevance and authority of the patient's narrative.

Further, patients with MUS have been found to express their symptoms with references to underlying psychological or social causes, or fears of specific diseases, (128) attributing symptoms to emotional distress, (124) or making references to stress, mood and life events, (49) and escalating their appeals to their physician through the use of graphic and emotional language when they felt they were not being listened to. (124) This may lead the physician to conclude that the patient is irrational or too emotional, contributing to stereotypes of the ill person as emotionally compromised, gripped by anxieties and fears about suffering and death (174) that detract from the illusion of any person's ability to be a completely rational actor. Physicians, with their rich biomedical expertise and well-practiced ability to reason, analyze data, and make sense of constellations of symptoms, may be particularly prone to believing that rationality in the face of illness is an attainable objective, and when patients are perceived as particularly irrational, they may especially be subjected to discreditation of their illness.

Patients with MUS often present complex and seemingly unconnected issues (130) and seek recognition of their distress, as well as emotional and practical support. (124) They may be felt by physicians to be particularly demanding of time and energy, leading to their illness narratives being cut short by physicians to prevent (or as a result of) frustration, or in an effort to avoid threats to the physician's authority. Fricker argues that particular strategies of expression result in the exclusion of some groups due to their characteristic expressive style not being seen as rational and contextually appropriate, (160) leading to a vicious cycle of more extreme styles of expression, which we see with patients with MUS when attempting to have their illness experience taken seriously, (46) and increasing frustration of all parties. (174) Experiences of illness, which are already difficult to communicate and make sense of (hermeneutical injustice) (172) are made to be more so when this communication difficulty, perceived incoherence and irrationality are weaponized against the patient, often times in the insinuation of psychiatric illness.

iii. The belief that patients with MUS suffer from psychiatric distress

In addition to signaling a lack of diagnostic clarity, labels such as MUS name a diagnosis in the category of psychiatry, conflating uncertainty, lack of clear causal explanation for the symptoms, with certainty about psychological causes for symptoms. (175) While the mechanisms of MUS are not clear, the labelling of these symptoms often entrenches unfalsifiable pseudoscientific constructs of MUS and somatoform disorders (82) and undue implications about the psychogenic nature of the symptoms. Some have argued that those who suffer from mental disorders are even more vulnerable to epistemic injustice than those with somatic illnesses, (176) given the global contributors of problems associated with and in part caused by the mental disorder, the higher value placed by physicians on objective evidence over patient reports, and the entrenched negative stereotypes associated with mental disorders, as well as the specific problems relating to the symptoms of their particular disorder decreasing their perceived credibility. (176) These factors can all be said to apply to the case of MUS. The negative attitudes that PCPs have towards patients with MUS are well documented (51,177) and can negatively affect the diagnostic process, (41) and physician's clinical judgement (101) in ways that physicians admit can harm patients. (51) The harms to which they are referring here are those more tangible ones such as missed diagnoses, confrontation in the clinical encounter, or prolonged suffering due to physicians' reluctance to address the patient's needs. Not accounted for within these harms are the ways in which patients with MUS, who are often believed and portrayed to have psychiatric illness, as though the absence of evidence for biomedical disease is sufficient evidence for this conclusion, are the epistemic harms of the undermining of their illness narratives.

There is a wealth of patient narratives and of quantitative data demonstrating that evidence of psychological distress, such as vocalizations of stress or signs of anxiety, contribute to delays in care (178) and that pain complaints expressed with more emotional language may be more likely to be dismissed, perceived as exaggerated and psychological in origin. (179) Alison Reiheld argues that this is one element of more far-reaching, nefarious stereotypes about women in pain, who are believed by many healthcare providers to be prone to over-emotionality which is seen as incompatible with rationality (180), making them particularly prone to having their illness testimonies discredited.

If patients in general are seen as psychologically dominated by their illness in a way that undermines their capacity to accurately describe their experiences, (171,176) then patients with MUS are even more apt to be perceived this way, given that MUS are commonly understood to represent the misinterpretation of psychiatric distress. Objective evidence, prioritized over the inherent subjectivity of the illness phenomenon, is even prioritized when there is not truly evidence–only the absence of, often taken to imply psychogenic causation of the symptoms. The symptoms of certain psychiatric disorders, such as dementia or schizophrenia, reduce the credibility of patient reports due to their symptoms of cognitive impairment or delusions (respectively) that are taken to discredit the entirety of patients' illness testimonies. (176) In the next section, quality of MUS that contributes to a similar loss of credibility is explored.

iv. The belief that patients with MUS are misinterpreting psychiatric distress as physical symptoms

Patients with MUS are often felt to be misinterpreting their bodily sensations and incorrectly interpreting psychological distress as physical phenomena. (20) They are made to feel as though they are unreliable, mentally unstable, or malingering. (181) They are believed to be incorrectly understanding their own experience, sowing an additional layer of doubt into the credibility of their interpretation and testimony of their illness. If MUS are believed to be the manifestation of the misinterpretation of psychiatric distress, then epistemic injustice becomes a *sine qua non* quality of medically unexplained symptoms. Whereas the decreased credibility of the ill person in general is related to the disvaluing of their subjective experience, and the stigma, symptoms, and lack of objectifiable evidence in psychiatric illness contribute to additional epistemic injustice, then MUS, understood as a psychiatric illness due to the lack of identifiable pathology, and believed to be a particular form of psychiatric illness in which the misunderstanding of bodily sensations is an essential quality, are a quintessential case of damage to epistemic authority. Against a background of doubt about whether patients with MUS are really ill, patients with MUS suffer both hermeneutic injustice in the implication that they are unable to interpret their own bodily experiences correctly, and testimonial injustice in the devaluation of their illness narratives which are seen as inaccurate, irrational, and incorrect.

v. The perceived conspicuousness of patients with MUS who work to prove they are ill

Patients with MUS, after being disbelieved or discredited by their physicians, often inadvertently through normalization of their symptoms and reassurance that fails to engage with their concerns, feel that they must work to be recognized as legitimately ill. Patients may engage in strategic behaviours to seek out biomedical legitimacy, including increasing the intensity of their symptoms, in response to normalizations that dismiss the presence of disease. (80) They may elaborate upon mentioned symptoms and catastrophize (125) and refer to more complex patterns of related symptoms. (128) In addition to modifying their illness testimonies in various ways, including simplifying them to focus on physical etiology, (65–67,97) perhaps in an effort to avoid aforementioned psychiatric causal attributions, they may also attempt to perform the sick role in an effort to become a ‘credible patient’. (44) These efforts may be seen as attempts to overcome the credibility deficit established by their physician’s response to their symptoms, and they are likely to backfire. In their efforts to become a ‘credible patient’, they may accrue more skepticism and negative feelings from their physician, as these efforts render them conspicuous from a psychobehavioural perspective. (101) The strategic behaviours they engage in to assert their already-undermined credibility may in fact contribute to further decreasing it, prompting doubt from the physician, or contributing to beliefs that they are feigning their illness. The previous contributors to testimonial injustice occurred in the context of symptoms that were generally believed to be true, however potentially exaggerated or misinterpreted, but the efforts to prove legitimate illness, in response to dismissed testimonies, contribute to further invalidating the patient’s illness testimony.

vi. The groups to which those with MUS disproportionately belong.

Despite a lack of scientific evidence for a genuine difference between genders, (48) unexplained, psychogenic and contested diagnoses predominantly affect women (30,68,69,86,88,89,181) and female sex, fewer years of education, lower socioeconomic status (78) as well as non-Western origin (69) are said to be risk factors for MUS. Here, I argue that there are two, interacting contributors to this disparity, which reflect two different ways in which testimonial injustice manifests itself. First, individuals belonging to these groups, already known to be taken less seriously by physicians, as evidenced by differential treatment of pain (based on race and gender), may be more prone to being identified as having MUS as a result of inadequate attention to their illness testimony and less rigorous investigation of causes for symptoms. In addition, the illness testimonies of these individuals may be less likely to be trusted and taken seriously because they might be more readily dismissed as incoherent, too emotional, irrational or illogical more frequently than more educated, affluent, and Western-originating men.

There are countless narratives of the undertreatment and dismissal of women’s pain, and data pointing to delays in the administration of analgesia relative to men (182) and protracted delays in the diagnosis of conditions such as endometriosis. (183) The evidence for the undertreatment of pain in Black patients is overwhelming (184–187) and exists for other non-white ethnic groups, as well. (185) Reiheld argues that these disparities may be based on doubt of patient testimony, (180) citing a study by Tamayo-Sarver that found that physicians were less likely to prescribe opioids to Black patients, a disparity which was greatest for conditions with fewer objective findings (migraines and back pain) compared to long bone fractures. (188)

This differential treatment may be seen as evidence of the testimonies of some patients being seen as less credible or important than others, a disparity that is exacerbated by the absence of objectifiable evidence to corroborate the patient’s suffering. Patients with MUS may be doubly victims to epistemic injustice in this sense, wherein their symptoms are not treated by virtue of a perceived lack of credibility, and are not as rigorously investigated owing to certain personal characteristics, including race, gender, social class and education level, that result in their illness narratives being taken less seriously. Implicit biases of healthcare providers are well-known to impact patient care, and it is likely that these are manifested through the affording of more credibility to the testimonies of some patients over others.

Additionally, patients who communicate in ways that are deemed to be incoherent, irrational or illogical may be more prone to having their testimonies disbelieved and undermined. This reflects the decreased credibility given to testimonies perceived to be more emotional or those deemed to be too impacted by psychiatric causes. That credibility deficit is further compounded by elements that may render a patient less capable of communicating in a way that is deemed clinically appropriate. Those who may not be well-versed in the functioning of healthcare systems may be overwhelmed or confused by the norms of the clinical setting. Those not having any knowledge of biological sciences or physiology may be faulted for their inaccurate and potentially confusing (to the physician who does not take the time to clarify) explanations of their symptoms. Those with illness idioms that differ vastly from the largely biomechanical idioms in the Western world may be seen as having particularly illogical narratives or irrational worries about their symptoms, and patients with accents or who otherwise have difficulty expressing themselves verbally in the language of their clinical encounter may find their physician impatient and eager for them to ‘get to the point’, or the relevant symptoms that prompted their visit, which may be different to the suffering patient than to the clinician.

All of these elements pertaining to social group and individual identity interact and impact the authority that is given to the patient’s illness narrative. In cases in which biomedical evidence of underlying pathology is lacking, this may be taken as undermining or even disproving the authority of the already-marginalized patient. Physicians’ existing epistemic privilege in the clinical encounter, and the ill person’s perceived decreased credibility in their ability to know, understand, interpret, and testify on their experience in the clinical setting, (160,167) are all exacerbated by conditions particular to MUS. Patients with MUS may be seen as especially unable to articulate their illness in a way that is acceptable in the clinical setting, and may suffer additional burdens of testimonial injustice, (which may spill over into other facets of their life and their personal relationships) and hermeneutical injustice, given that the experiences of their MUS are especially difficult to communicate and make sense of. These epistemic harms, and the dynamics of communication they engender, contribute to additional, often more tangible harms to patients with MUS, which are explored in detail in the next part.

Part D: Harms in the Labelling, Communication and Management of MUS

The literature review in Chapter 2 brought to the fore the various ways in which PCPs fail to respond to the needs and desires for care expressed by patients with MUS, often through consultation styles, responses to patients and approaches that reflect inattention to the illness experience of the patient, in favour of a focus on the (absence of) disease. This inattentiveness to the illness experienced by patients with MUS, as well dismissal of their concerns, speak to the testimonial injustice suffered by ill persons in clinical settings, which may be exacerbated by a number of intersecting factors particular to MUS. This contributes to iatrogenic processes such as perpetual, unsuccessful searches for causes for symptoms, stigma associated with certain diagnoses and implicit in labels, and over- or undertreatment, among the ways that patients with MUS may be additionally harmed in the primary care consultation. This section will explore these issues through a consequentialist framework, examining explanations for potentially harmful elements of the consultation, and interrogating how focus on disease and clinical uncertainty in its absence, contribute to these harms. Doing so elucidates issues with care for patients with MUS by assessing common practices and laying the groundwork for further inquiry, and where relevant, interrogating the relationship between risks, harms, and benefits of particular practices.

i. Failure to listen to and engage with the patient’s needs and concerns

In the critical interpretive review in the previous chapter, it was revealed that patients have multiple explanatory models for their symptoms, with complex and fluid understanding of their symptoms that rely on a variety–often more than one–of mechanisms, including psychological and social mechanisms. Their expectations of their physicians and desires for care may be made explicit or suggested, such as through suggestions of psychosocial explanations (37,125,127) and references to a range of underlying concerns in the hopes that physicians address them. These underlying concerns were varied, including relating their symptoms to underlying medical, psychological or social causes or fears of specific diseases, (128) suggesting biomedical explanations or attributing symptoms to emotional distress, (124) or references to stress, mood and life events. (49) When they felt they were not being listened to, patients escalated their appeals to their physician through the use of graphic and emotional language and referring to the impact of symptoms on their daily lives, attempting to compel physicians to address their concerns and validate their experience. (124) Patients also made more explicit requests for care, expressing that they wished to have explanations for their symptoms, support, listening, honesty and attention, validation, and coping strategies, among others. While some physicians did explore the symptoms, clues and concerns expressed by the patients, most of the explorations did not engage with the underlying concerns of the patients (128) and GPs often provide simple reassurance that does not engage with patient concerns. (103) To position this in the broader context of patient-physician communication, it is a relatively common feeling among patients and in the broader social discourse that physicians do not listen to patients and patients often do not feel heard by their physicians. It is telling that research shows that patients may be interrupted approximately twelve seconds into primary care encounters, (189,190) which may be evidence of a tacit assumption about the capacities of patients to provide relevant information in healthcare contexts, (174) and may be even more so in the case of patients with MUS, whose narratives are often perceived as particularly unwieldy and not credible.

This may be summarized as a failure to listen to the suggestions and explicit clues patients provide about their needs, desires for care, and concerns about their symptoms. In this section, building on the significant burden of epistemic injustice faced by patients with MUS outlined in the last section, I argue that this results in patients not feeling heard, PCPs potentially missing important symptoms or patient clues to underlying stressors or concerns, and PCPs' ineffective responses to patients, each of which may lead to conflict and contest[10] between patient and physician and the offering of unnecessary somatic intervention. (103)

PCPs' difficulties in listening to MUS patients may reflect a number of interacting factors, among them, many physicians' frustration with patients with MUS, (41–43) physicians feeling that they do not have time to engage with these concerns, or that full exploration of patients' concerns and worries does not fit into the traditional, physician-led, standard biomedical clinical

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[10] Contest consists of the patient trying to convince the physician that they are ill and in need of their help, described as a 'tug of war' in which patients escalate their concerns and emphasize their suffering, while physicians minimize these through normalization and disengagement. (103) Conflict may emerge from this contest or present itself as more explicit disagreement.

encounter, in which physicians ask directive questions to get to the (pathophysiological) root of the symptoms, and in which patients have limited time to express their illness experience. All of these specific limitations physicians face in their desire and ability to listen to the ill patient speak to the paternalistic structure of the patient-physician relationship, which places the physician in a position of authority and epistemic privilege (167) predicated on their professional expertise. (191) These are compounded in the MUS consultation, perhaps related to individual qualities of the patient and to the perceived challenge to physicians' epistemic privilege in the absence of biomedical evidence for the symptoms. In fact, patient-related factors, such as multiple or severe symptoms, (192,193) symptoms perceived to be vague or somatoform, and higher degrees of multisomatoform and other psychiatric disorders in patients, (109) contribute to physicians perceiving patient encounters as difficult. Physicians with worse psychosocial orientation scores report more challenging patient encounters, (193) and those with no training in communication or counselling skills reports twice as many 'heartsink' patients (as opposed to those with some formal training in these subjects). (99) Those with lower job satisfaction and with acute increases in workload tend to perceive more of their patient encounters as difficult. (99) Physicians who are overburdened with the responsibilities of the clinical encounter may be particularly prone to discounting the patient's narrative when it is leading to what they feel will be a challenging patient encounter. If they can redirect vague symptoms or minimize and attenuate patient concerns, they may be better positioned to dismiss the patient's concerns through what they perceive to be reassuring statements about normal results or non-worrisome symptoms.

Most directly, not listening to patients can be harmful. While the literature is limited, there is some evidence for a therapeutic effect of listening[11]. Listening plays a crucial role in recognition of the patient's suffering; inherently validating the patient's experience as it implies that there is something to listen to. (194) It may also minimize the anguish and alleviate patient suffering, in part through inducing self-reflection. (195) PCPs failure to explore MUS patients' concerns has been identified as a barrier to diagnosis of non-specific, functional, and somatoform disorders (41) and may additionally make it difficult to differentiate between symptoms that are

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[11] Which seems sufficiently intuitively obvious so as not to require overwhelming empirical evidence to support this relationship.

medically unexplained and those that are somatoform in nature. PCPs admit to psychologically disengaging from their patients and many decline training to improve their psychosocial skills with these patients. (177) It has been argued that PCPs' well documented negative attitudes towards patients with MUS (51,177) can negatively affect the diagnostic process, (41) which is corroborated by feelings expressed by some GPs. (51) This may result in missed diagnoses, prolonged suffering of the patient due to PCPs reluctance to address their needs, and unnecessary confrontation that compromises trust and therapeutic effectiveness of the consultation. These may bear more broadly on the patient's life, impacting their epistemic confidence through gradual erosion of their credibility, (174) causing them frustration and further distress, with effects likely extending to the patient's relationships and social interactions.

The extent to which physicians struggle with patients with MUS is alarming, and some physicians admit that negative feelings affect their clinical judgement, (101) and note that the strained physician-patient relationship could be harmful to the patient. (51) Notable statements from GPs in a qualitative study of challenges in the clinical consultation included: "I felt I lost my judgement with her because I dislike her." and "You can get yourself into the position where you will never spot an illness in this patient if it was staring you in the face and they were dead on the floor, because you will feel it's just their bloody somatising." (51) To be clear, these GPs were referring to primary care patients with unexplained symptoms that the GP attributed to somatization due to psychological distress. Thus, these reflected the GPs' broader sense of powerlessness in consultations in which there was no clear medical explanation for symptoms, (101) suggesting that the combined absence of medical explanation and particular personal characteristics of the patients themselves creates a situation in which the GP may be unable to care for patients and may unwittingly neglect to investigate dangerous causes for symptoms or offer symptom management strategies that do not require a medical understanding of symptom etiology. In their difficulty in attending to patients with MUS, PCPs may fail to appreciate patients' suffering and neglect their commitment to the well-being of the patient and the principle of beneficence, (196) which includes providing appropriate care and management to patients. (169)

Moreover, the physician may fail to listen and engage as a defensive strategy out of fear of needing to deny a patient request and enter into a confrontation. They may also do so to maintain control over the consultation, as physicians have been found to experience problems of control in MUS consultations, feeling as though they may threaten their authority and cause them to lose their power to direct and control the course of events. (51) The power structures of the standard clinical encounter, the nature of the patient's symptoms and the way they express themselves, and qualities of both the patient and the physician, in short, may implicitly undermine the credibility of the patient and inflate that of the physician, making listening and engaging with the patient's desires for care and concerns more challenging, and may result in physicians forgoing their moral duty to treat patients beneficently as a result of their lack of professional authority over the symptoms and interpersonal challenges with the patient.

The potential harms of failing to listen to and to engage with the patient's concerns are numerous and interacting. These include the possibility of mistakenly attributing symptoms to somatization due to the absence of evidence of an underlying pathology and interpersonal challenges with the patient, in addition to prolonged suffering of patients who must attempt to prove to their physicians that their MUS are legitimate and valid in order to be recognized. (46)

As a result, patients may feel that they are being dismissed or invalidated by their physician early in the consultation, discouraging them from disclosing other concerns, causing them to avoid seeking medical care, and feeling that their illness is being doubted or invalidated. Downstream consequences include worsening distress and exacerbating symptoms, perhaps related to a feeling of doubt in the patient's experience as a result of this indirect rejection of their account of their illness, which may undermine their perceived authority over their body and their experiences. Patients may go on to withhold information in future consultations, at the risk of their own health, for fear of being made to feel untrustworthy or not deserving of the physician's attention. Patients with persistent somatoform disorders of greater than two years were found to have no expectations from the healthcare system, not expecting the legitimization of their symptoms, only that they not be dismissed, (65) which paints a bleak picture, illustrative of a history of alienating and invalidating interactions with the healthcare system.

Not allowing the patient to recount their illness history may be influenced by a fear that they will take more time than is available to PCPs in systems in which they are required to fill their schedules with short clinical encounters and expected to address numerous patients' concerns. Nonetheless, patients may not always need quite as long as physicians fear they do, with some uninterrupted patients taking just six seconds to state their concern, (190) though this, evidently, is not representative of patients with more complex concerns, or those who feel that they must fight to have their voice heard, and who attempt to illustrate the severity and validity of their symptoms through intense language and vivid, complex descriptions. (46) Consequently, failure to hear out the patient's concern may result in the patient requiring more time, potentially over several visits with their physician in an effort to have their experience heard and validated. While limited time is necessarily a relevant concern for PCPs with tightly scheduled appointments with patients, this does not excuse nor explain neglecting or ignoring patients' concerns. While PCPs may not necessarily be adequately trained in communication and may struggle with patient encounters they perceive as challenging for any number of reasons, with some citing a feeling of inability to explain symptoms or help patients, (42,177) ignoring patients' escalating expressions of concern over their symptoms, intense language to emphasize the abnormal and involuntary nature of symptoms, (46) and direct disclosure (37,125,127) and implicit allusions (49) to their worries and concerns about their symptoms is undoubtedly harmful to some patients and does not seem reasonably attributable to a lack of skill on the part of the physician. Concerns that the patients with MUS may make unreasonable request for somatic intervention or pressure the physician into providing care appear to be unfounded. (33,37) A fear of being unable to address emotional or social issues or maintain dominance and authority over the consultation does not justify a failure to listen and appropriately communicate about patients' desires for care and their concerns about their symptoms.

There is no doubt that conflict in the clinical consultation is challenging and harmful to both physician and patient. One might question to what degree the physician is responsible for listening to the patient's account of illness and their worries or concerns, and to what extent these must be considered when they are deemed to be inconsistent with known disease aetiologies. These are two separate questions, which tend to get conflated. Models of patient-centered care emphasize the importance of attending to the patient's illness experience, their unique perceptions, feelings, priorities, concerns, and goals of care. (19) Exploring these with the patient and listening to their concerns may be time-consuming in the short-term, but can contribute to the establishment of a concordant patient-physician relationship in which the PCP understands the patient’s worries and establishes rapport with them that does not require for these to be expounded at every visit. Given the relationship-based model of primary care, (170) this is not only ethically favourable, but likely to contribute to better care and an improved patient-physician relationship. The second question, pertaining to the extent to which the patient’s worries and fears about illness and disease must be addressed, often arises due to a mistaken assumption that the easiest way to address these is by investigating them biomedically and offering the patient proof via the provision of normal test results. This not only negates the important role of communication that engages with the patient’s concerns, but incorrectly assumes that the provision of normal results is inherently reassuring to patients.

In many ways, this failure to engage with patients’ concerns in the MUS consultation, in which evidence of underlying disease is lacking, may not only be harmful to patients by denying them the opportunity to have their suffering heard and attended to and by failing to address their underlying concerns, potentially missing clues to serious stressors or signs of underlying disease. It also raises the question of the physician’s responsibility to care for patients in the absence of identifiable pathology and highlights the ways in which PCPs hold onto power, relying on their professional authority defensively within the consultation.

ii. Offering of normalizations and reassurances

PCPs often offer normalization or reassurance in response to the symptoms disclosed by patients with MUS. Normalization and reassurance generally refer to strategies employed to respond to the patient’s symptoms by expressing that the symptoms are not of significant concern given the absence of physical disease, (50,145) occasionally with rudimentary reassurance and appeal to the authority of negative test results, (80) or other simple reassurance that does not engage with the concerns expressed by the patient. (103) They may state that symptoms are a normal part of life, (42) or offer tangible, hypothetical physical mechanisms to explain the symptoms, which often are not linked to the patient’s concerns, and may imply that healthcare intervention would be unnecessary. (80) Sometimes, they may even say “nothing is wrong,” or otherwise express that there is no disease. (42) Generally, these are attempts to reassure the patient and alleviate their concerns and fears–using the information from physical examination and medical investigations as evidence of lack of pathology–that the absence of underlying disease means that their symptoms are not to be worried about. The intent, in most cases, is undoubtedly benevolent; the physician using their knowledge, the biomedical data they have collected, and their professional expertise and authority to offer what they perceive to be relatively conclusive evidence that the symptoms the patient is experiencing are not dangerous or worrisome. The intent may additionally include informing the patient that further medical investigation and intervention is not necessary, and purposefully emphasizing that it will not be happening, perhaps to pre-empt requests for unnecessary interventions.

Normalization and reassurance are not inherently or necessarily harmful, in fact, they are likely to be part of an appropriate and effective response to MUS if they are employed in a way that is responsive to the worries patients express, and if the mechanisms used in normalizations validate the patient's suffering, are tangible, and offer the patient the opportunity to make the connection between the physical symptoms and the psychosocial dimensions of their life. (34,80) What is problematic is that many of the normalizations and reassurances offered to patients fail to engage with what patients are concerned about when seeking care for their MUS, (likely as a direct result of the issues discussed in part i). After failing to listen to patient's worries and underlying concerns about their symptoms, and not engaging with these in any meaningful or responsive way, it is the expected sequitur that the reassurances and normalizations offered do not address patients' concerns. While it is necessary for the physician to inform the patient of the (normal) results of their investigations, with the CMA Code of Ethics requiring physicians to "[c]ommunicate information accurately and honestly with the patient in a manner that the patient understands and can apply," (169) this process of communicating the normal results of investigations, often paired with reassurance, needn't deny, directly or implicitly, the patient's experience of symptoms. The same article in the CMA Code requires that the physician "confirm the patient's understanding," (169) speaking to a duty of the physician to engage in some capacity with the patient and ensure that the information offered is understood and more broadly appreciated in the context of the patient's experience.

The challenge of communicating normal results is rooted in the epistemic problem of MUS elucidated in the first chapter, that the physician's sources of information are inconclusive (in the context of negative investigations), and they cannot rely on their professional authority alone (31) to support the normalizations and reassurances they offer patients. Yet, patient and physician may co-construct an appropriate explanation or normalization that provides a satisfactory representation of illness that addresses the patient's worries in a way that provides relief. (101) For example, speculative pragmatic explanations, proposed by Greco, may offer a "prospective, proactive and prescriptive" truth (197) that shapes the embodied experience of the patient towards an alternative future in which symptoms can resolve. (101) Some might conceive of the physician's role as one of rectifying the patient's illogical worries or irrational beliefs about their symptoms. This should not be the case and is based on the presumption of rationality we use in our attempts to make sense of human behaviour and beliefs, which rarely holds. Patient's worries and fears should be explored and addressed by the PCP, but it would be a mistake to try to quash these with biomedical evidence. This approach–to disprove the patient's fears through the provision of evidence–is consistent with the information deficit model, which attributes erroneous public beliefs about science to be caused by a lack of evidence. (198) Despite acknowledgement in the behavioural sciences that this model does not hold, (199,200) corroborated by overwhelming evidence in the form of climate-change deniers and others not convinced of any number of phenomena that are overwhelmingly supported by scientific evidence, it is still being used in medicine in an attempt to disprove beliefs that are seen as irrational or unfounded using biomedical evidence. This reflects the lack of testimonial authority given to patients, in these efforts disprove their illness experience with an absence of evidence, as well as a failure implement patient-centered methods in practice, in which a dialogic approach to communicating about these concerns and finding common ground (19) would be more consistent with patient-centered care and likely more effective.

Sometimes, reassurances and normalizations are offered to patients as though not having identified a pathology is evidence of a lack of pathology, and as though the physician has put to rest the question of biological disease. (48) This approach creates an irreducible contradiction between the medical 'truth' of there being no disease and the patient's experience of suffering. (101) While there may in fact be no underlying pathology to which the symptoms can be attributed, this cannot be proven, and even if it could, it does not justify communicating with patients in a way that dismisses their experience. Instead of acknowledgment of the inherent uncertainty of symptoms that are medically unexplained, normalizations and reassurance often rely on the idea that there is nothing wrong if the results of investigations are normal. This has the unintended consequence of patients not feeling reassured, and sometimes responding with more intense and robust presentations of their symptoms or introduction of new symptoms, associated with an increased likelihood of somatic management. (80,103) Recall that normalization without explanation was effective in established, trusting therapeutic relationships, (118) where the existing bond between the patient and physician may dispense with the need for explanation or further engagement, given the existing trust. Conversely, in new therapeutic relationships, it was associated with the lowest levels of patient satisfaction. (118) This provides support to a patient-centered approach that relies on establishing rapport with the patient through communication and discussion of their ideas about health, experience of illness, and worries about disease. (19) Reassurance that MUS do not signify an underlying medical issue has led some patients to feel their concerns have been dismissed and their provider is uncaring, (123) rather than experience the intended benefit of eliminating these concerns.

The strategies employed to reassure patients that their symptoms are not due to an underlying, concerning disease and to normalize their symptoms as a part of life not to be worried about cause many patients to feel as though their experience is being dismissed. This approach conflates the absence of evidence for an underlying pathology with the false assumption that the symptoms have no cause. While it may be reassuring to the physician that there is no evidence of an underlying pathology, "normal" test results are not as reassuring to patients as they are commonly believed to be. (38,201,202) Patients with negative illness perceptions may be even less reassured, (202) and premature reassurance may paradoxically raise patients' anxiety. (203) This speaks broadly to the prioritization of disease over illness as the extension and manifestation of the power dynamics between patient and physician, and between the subjective illness phenomenon and the perceived superiority and objectivity of biomedical sciences, (81) with the physician acting as the ultimate holder and gatekeeper of biomedical knowledge.

Dismissal of patients with MUS and disregard for their concerns may lead them to amplify their symptom presentations in order to be heard, among other attempts to get the attention of their PCP. Intensifying their accounts of illness may lead to unnecessary, and potentially harmful somatic interventions. (103) Patients may continue in a cycle of seeking a medical diagnosis, undergoing potentially dangerous evaluations and investigations, and being repeatedly told that all medical tests are negative, often in ways that directly deny or are perceived to deny their lived experience of illness. They may become disappointed with the ongoing lack of a clear answer, and subsequently seek out “better” or more specialized clinicians or consultants who might offer a satisfactory (but potentially spurious) explanation. Jimenez and Mayer attribute this process to clinicians’ reluctance to recognize, discuss, or acknowledge MUS in any capacity other than the lack of evidence for an medical explanation. (82) Patients may worry about diseases for which they have not been investigated, and this worry may go on to worsen their illness perceptions and illness-related anxiety, making them less likely to be reassured by normal test results.

The extent of the harms of this response by physicians is not known, and difficult to isolate and investigate, given that it is but one element of an individual’s experience of living with MUS, and likely impacts other elements of their care and interactions with others both in and outside of the healthcare system. The answer is not to investigate for every possible disease–this would be unreasonable, harmful, and a misplaced attempt to placate the patient–rather, clinicians ought to communicate with patients about their symptoms in a way that engages with patients’ underlying concerns and that opens up honest discussion about addressing MUS, including the limitations of diagnostic testing and the available care and symptom management options.

iii. Explanations offered

In place of normalization and generic reassurance, some physicians attempt to provide explanations for a patients’ symptoms, employing metaphor to present hypothesized interactions between symptoms and psychosocial life, often with reference to an imbalance between load and capacity (42) or other tangible mechanisms linking physical and psychosocial factors. (80) Some PCPs offered considerations of various explanations, including physical, psychological and social causes. (138) Explanations may give the patient agency over the symptoms through descriptions of biological or psychosocial processes that are within the patient’s control, while others link an involuntary physiological process to consequences (the symptoms), placing the causal responsibility away from the person, to “create distance between the patient and problematic body, which is typical of a conventional biomedical clinical interaction." (140) Some explanations were complex and chaotic, and referred to intricate hypothetical interactions between body systems, described as vicious cycles, (140) while others relied simply on defining the symptoms or attributing them to a triggering event or a precipitating factor. (145)

While some of these attempts to explain the symptoms accounted for patients' own explanations and involved physicians and patients co-creating explanations, many disregarded explanations offered by patients. Considering the absence of identified pathology and thus the physicians' lack of authority over the patients' illness in the absence of biomedical evidence, their authority to provide an explanation in this context is questionable. Explanations that fail to engage with patients' expressed concerns and illness models may be similarly dismissive to normalizations and may additionally cause patients to unduly focus on causes or mechanisms that are not at fault. For example, in cases in which physicians might attribute symptoms to overexertion or too much activity, and suggest decreased activity level, which is a management strategy occasionally offered for MUS, (147) patients might go on to progressively or drastically decrease their activity level in the hopes of alleviating symptoms, potentially with some relief related to placebo effects and possible elimination of a particular stressor associated with their activity. However, this comes at the cost of decreased physical activity and eventually difficulty in maintaining other activities of daily life that bring them joy or value. Other causes that refer to posture, mechanistic factors, or involuntary processes of the problematic body (140) take agency away from patients and may lead to excessive worry or concern about particular movements, their own vulnerability to stressors, or a perceived inability to tolerate generally innocuous activities, without evidence that these are to blame. These explanations perpetuate a narrative of weakness and dependence, without offering an effective or evidence-informed management strategy. A patient-centered approach, conversely, would empower the patient as an agent of their own health, working with them to identify possible symptom triggers and adapting this exposure based on a need to learn to tolerate these or eliminate nefarious symptom triggers when appropriate, involving the patient in the process of defining the problem and creating solutions, employing the physicians' biomedical knowledge and evidence-based approaches, informed by a holistic perspective on their illness experience and lived context.

Explanations offered may be stigmatizing to patients, offering psychological explanations when patients have not disclosed psychological or social stressors, invoking blame or fault for their symptoms and invalidating the patient's experience: attributing it to psychological stressors without just cause. This further undermines the patient's authority over their illness and their body, offering unfalsifiable, untestable explanations without having collected the information from the patient to support the physician's claim. Attributing a psychological cause to the patient's symptoms without exploring these is effectively expressing that the physician has more authority over the patient's lived experience without more than a cursory exploration, than the patient does over the experience that they live. In fact, patients have been found to interpret psychosomatic attributions for their symptoms as face-threatening 'other positionings', experiencing pressure from clinicians to accept the attribution, and frequently rejecting it. (35) Psychological labelling of symptoms without consideration for the patient's experience may further reinforce a dichotomy between 'real' medical symptoms and 'fake' psychological ones, which needn't be the case if the patient's psychosocial context is explored and attended to.

Given that many patients offer emotional and psychosocial explanations for their symptoms, (50,65,67,114,118) they may be ready and willing to co-create these explanations with physicians, offering their authority over their illness experience, while the physician employs their expertise and clinical skills to ensure that the explanation offered is medically coherent and actionable. Without this collaborative process, though, explanations offered by physicians that rely on untestable mechanisms in the absence of biomedical evidence and that do not engage with patient's own explanations, are not truthful, may be perceived as dismissive and stigmatizing, and may cause harms to patients in a number of ways, in part by undermining their agency and invoking blame. Though explanations offered to patients with MUS may have a therapeutic effect by allowing them to make sense of their symptoms, those that do not account for patients' concerns; that attribute the symptoms to a hypothesized vulnerability of the patient or that undermine patients' authority over their mind and body may be stigmatizing, dismissing, blaming, or create dependency on the clinician. Clinicians are likely well intentioned when offering these explanations, unaware of the harms they may cause, or wishing to avoid the iatrogenic process of seeking an explanation described in the next part.

The explanations provided for MUS additionally raise a question of the physician's duty to communicate honestly. (169) In the face of uncertainty about the etiology and the cause for symptoms, which is related to the difficulty in systematically and methodologically investigating and integrating the biological, psychological and social in clinical practice, (17,18) the absence of biomedical cause for the symptoms, as well as the failure of PCPs to truly investigate patient's psychological and social context, how can the PCP offer an explanation that is sufficiently honest? In many ways, the uncertainty about the symptoms reflect the state of medical knowledge, and the limited integration of behavioural sciences and psychology into biomedicine, despite several decades of discussion of the biopsychosocial model. The uncertainty additionally reflects the limitations of the particular clinicians' expertise and experience, as well as their biases and beliefs. In the final chapter, an approach that allows for the construction of honest and acceptable explanations for MUS will be offered.

iv. Searching for an explanation and validation: the iatrogenic process

Unsatisfactory responses to patients' symptoms range from cutting off the patient and engaging in non-alliance, (implying that the patient should not consult with problems of this nature (42)) to beneficent attempts at normalization, reassurance, and providing explanations for symptoms (expressing that the patient shouldn't worry about or attempt to find meaning in the symptoms experienced). Any of the responses to patients' symptoms that are unsatisfactory to patients and fail to engage with their concerns may result in a perpetuating, protracted iatrogenic process of seeking a diagnosis or other forms of medical attention. This iatrogenic process[12] may be attributed to clinicians' reluctance to recognize, discuss, or acknowledge MUS in any capacity other than the lack of evidence for an medical explanation. (82) The consultation itself may be iatrogenic, by entrenching focus on physical problems (98,102,103) while simultaneously dismissing the patient's experience of symptoms and failing to acknowledge

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[12] A process wherein patients undergo potentially dangerous evaluations and investigations, are repeatedly told that all medical tests are negative, feel dismissed and disbelieved, and in their disappointment with the ongoing lack of an explanation, seek out new, "better" or more specialized clinicians or "super consultants" who might offer a (potentially spurious) diagnosis.

diagnostic uncertainty. While it can be argued that it is not the PCPs' responsibility to manage MUS, primary care seems most appropriate to address symptoms of this nature; most GPs feeling these symptoms should be managed in this setting, (40) and it remains the responsibility of the primary care provider who has professional responsibility for their patients to continue to provide services until another suitable physician has assumed responsibility for the patient. (169) Responses to patients with MUS such as non-alliance or others that dismiss these patients without endeavoring to consult a relevant specialist or other clinician who may be better suited to these patients' needs is reneging on one's professional responsibilities as a physician while simultaneously implying that the patient is both at fault and responsible for their symptoms.

In the ongoing search for validation of their experience and medical care that addresses their concerns, patients may undergo continued biomedical testing that can cause unjustified harms. It is challenging, in the context of MUS, to determine the balance of risks and benefits in the process of investigation for causal pathologies. PCPs have cited fear of missing a serious somatic diagnosis as justification for significant investment into primarily medical investigations and somatic care (204–206) as well as concern about undermining the patient's biomedical beliefs about their symptoms, (206) despite the extensive evidence reviewed previously that patients hold a variety of causal explanations for their symptoms. Potential harms associated with diagnostic testing may be significant, and the risks of, for example, intestinal perforation during colonoscopy for the investigation of abdominal pain, may be substantial and unacceptable in the cases in which the physician's assessment of the patient leads them to conclude that it is unlikely for this investigation to offer further insight into the patient's symptoms. Jimenez and Mayer argue for an honest discussion of risks and benefits of evaluation and procedures in MUS in order to communicate the presence of risk without therapeutic benefit and identify defensive medicine and a lack of validated screening tools for the identification of abnormal illness behaviour as contributing to iatrogenic investigation processes. (82) A thorough assessment and open communication with the MUS patient, without premature assumptions about somatization and implied psychogenic causation which may not only blind the physician from the possibility of harmful disease, but render honest communication about investigation virtually impossible, may help mitigate the risk of unnecessary and potentially harmful medical investigations.

Jimenez and Mayer also argue that the possibility of obtaining informed consent may be undermined by continued requests for testing and ongoing investigation. (82) While these persistent requests for ongoing investigation by patients are not as widespread as they are believed to be, in the cases where these requests persist beyond what is determined to be appropriate investigation of the symptoms and reassurance, it may be a case in which the patient's worries about their symptoms and concerns are truly irrational and intractable, in which case it would be worthwhile to investigate the psychological contributors to these persistent and unmanageable fears. In most cases, however, rather than interrogating whether the patient is fit to provide informed consent for potentially harmful investigations, it would be more worthwhile to assess whether the communication about their symptoms has addressed the concerns they repeatedly express. It may well be the case that ongoing requests for somatic investigation and intervention are the result of societal beliefs, reinforced by the physician who has primarily offered these in response to their concerns, that these are the only way to address any illness fears they have. The physician is likely to have contributed in some way to these ongoing requests. A patient's perceived inability to provide informed consent may reflect them having been inappropriately informed by the physician, it is not necessarily the consequence of inadequate cognitive abilities on the part of the patient. This is additionally consistent and part of a broader discussion of the flaws in our understanding of informed consent, which relies on the belief that provided with enough information, the competent patient should be able to make a rational decision, consistent with the (flawed) deficit model of scientific communication.

Decisions to stop pursuing investigations are complicated by the impossibility of establishing that symptoms have no underlying pathophysiological cause; one cannot prove a negative, as well as cognitive biases that make us favour doing something (investigating symptoms) over doing nothing, even when doing something may cause harm. MUS may ultimately reveal themselves to be caused by a previously unidentified pathology or a rare or difficult to diagnose disorder–mistaken psychogenic diagnosis is common in a number of rare diseases and may take years before it is rectified (207)–though it is unlikely that rare diseases underly the up to 50% of primary care consultations that concern symptoms that are medically unexplained. (29) The fundamental uncertainty associated with MUS demonstrates how they act as a limits case of EBM, symptomatic of a deeper, underlying philosophical issue that is not resolved by treating MUS as an empirical problem to be solved, as though we are waiting for an explanation to reveal itself. (31) PCPs contribute to this issue by responding to patients' symptom presentations in ways that invalidate and dismiss their experience, implying that the absence of evidence for a causal mechanism means that there is nothing worthy of concern, leading the patient to continue to pursue medical care until an object of medical interest is revealed or a clinician validates their experience biomedically. Physicians' responses to their MUS may, in a sense, 'train' patients to believe (or reinforce existing beliefs) that this is the only way of obtaining care. As this process continues, expectations of an elusive biomedical explanation may increase in some patients, while others may resign themselves to a fate of uncertainty and lose hope in the medical establishment, as it has failed them. Individuals self-identified as having contested illnesses such as chronic fatigue syndrome and multiple chemical sensitivities report undergoing protracted and difficult processes in the quest to claim medical legitimacy, questioning their own state of mental health when initially given psychological explanations, eventually rejecting these and attributing them to physicians' lack of knowledge about their illness, investigating other explanations for their illness on their own, and seeking recognition and acceptance. (208) While there is contention over the utility and benefit of diagnosis with a contested illness, the trajectory towards these diagnoses is unjustly harmful to patients.

The harms of this process of medical assessments and investigations, whether due to PCPs' concern of missing dangerous underlying disease, patients' search for medical legitimacy, or both, are clear: patients remain in a perpetual state of doubt and uncertainty, questioning their illness experience and their state of mental health, their authority over their experience, and their worth and merit in seeking medical care. This is a quintessential example of epistemic injustice. Patients with MUS are made to feel as though they are unreliable, mentally unstable, or malingering. (181) These perceptions of patients and various unexplained, psychogenic, and contested diagnoses predominately affect women without scientific evidence for a genuine difference between genders. (48) Patients may hold onto the belief that with enough investigation, a pathology will reveal itself, and PCPs biomedical approach may reinforce this belief. Of course, this may never be the case, and contested illness diagnoses do not rely on the identification of a pathology, rather an inexact process of exclusion and diagnosis using formal criteria, such as for fibromyalgia, (209) which are inconsistently applied in practice and frequently take considerable time and tenacity on the part of the patient to find a health care provider who believes in these conditions and is willing to diagnose and treat them. (181,210)

Many unexplained symptoms will spontaneously resolve, (211) which encourages consideration of how the iatrogenic elements of the consultation, and potentially even MUS or contested illness diagnoses, may contribute to symptom persistence. While contested illness diagnoses generally afford sufferers considerable peace of mind and validation after long, protracted experiences of suffering and disbelief (181)–I posit that these diagnoses become more necessary as a result of the suffering induced through dismissal and invalidation at the hands of some physicians, and that their utility and benefit is in response to the iatrogenic suffering more so than the suffering related to the symptoms themselves. Greco distinguishes these as secondary and primary suffering, respectively, and identifies physicians' somatic focus as a contributor in physicians co-production of the reality of somatization. (101) In short, the clinical consultation may make patients focus somatically, exacerbating their symptoms and causing them to perform the sick role to become a 'credible patient', (44) perhaps adopting an idiom of explanation that focuses on the physical etiology of symptoms at the expense of their typically more nuanced idioms. (65–67,97) These efforts backfire, rendering the patient 'conspicuous' from a psychobehavioural perspective, prompting further skepticism and negative feelings from the physician, and renewed patient efforts to establish their credibility. (101) This may even impact patients' physiological capacity for self-regulation, (101) causing them to lose their prerequisite skills for wellbeing, ability to discern among symptoms, and cope, making them more vulnerable. (212) This describes a process by which the patient is made to engage in strategic behaviours to seek out biomedical legitimacy by systems and physicians that require biomedical evidence to treat illness as legitimate, a process that may exacerbate patients' symptoms, drive the ongoing pursuit of unnecessary medical intervention, and further frustrate physicians when they perceive the patients as conspicuous and 'acting' or feigning their illness. For the patients themselves, they may become less resilient, more vulnerable to symptoms and stressors as a result of needing to work for medical validation. Given the physician's duty of non-maleficence, (196) their contribution to this iatrogenic process is problematic, and it is necessary to change the systems and patient-physician dynamics that contribute to these lasting harms to patients through unnecessary and risky investigations, prolonged uncertainty and fixation on the belief that with enough investigation, a diagnosis will reveal itself.

Greco describes how this patient-physician dynamic sets physical and psychological explanations to emerge as mutually exclusive alternatives. (101) In the next section, labelling of MUS is considered, and the false dichotomy between physical and psychological symptoms as it relates to the conflation of uncertainty with psychogenic causation is discussed.

v. The harms of conflating uncertainty with psychogenic causation

Several factors operate concurrently to contribute to assumed psychogenic causation for symptoms and related stigmatizing labelling of MUS. These include lack of clarity regarding the nature of MUS, combined with the conceptualization of physical and psychological explanations as mutual alternatives, the relationship between MUS and the construct of hysteria, and the use of negative criteria for the diagnosis of MUS and related medically unexplained conditions. This section explores how these phenomena interact to conflate uncertainty about the nature of the symptoms with implied psychogenic causation to the detriment and invalidation of patients.

MUS as a concept suffers from substantial ambiguity, with two distinct and often poorly delineated meanings for the term. Commonly, MUS is used to refer to symptoms that are unexplained medically and have primarily psychosocial causes, (28,48) despite this attribution of symptoms to psychosocial causes often being made without genuine exploration of the patient's psychological and social context. This definition is in contrast to the broader sense of all symptoms for which a patient seeks medical attention and for which an underlying explanatory pathology cannot be identified[13]. The unexplained quality, in this case, lies in the limitations of the biomedical ontology, and not an inherent quality of the symptoms themselves. MUS as it is employed in this thesis is an analytical concept to denote a heterogeneity of symptoms that are as of yet, unexplained within the reductionist biomedical model, with an understanding that the determination that the symptoms are unexplained is not infallible nor objective. O'Leary makes a similar distinction, labelling the subset of MUS that have primarily psychosocial causes as

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[13] See Chapter 1, part C for a more thorough explanation for this choice.

“psychogenic symptoms”. (48) This distinction is supported by the 2013 5th edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5), which discouraged the use of the term MUS to signify that symptoms are psychogenic in nature. (52)

The substantial terminological ambiguity not only has the effect of clouding clarity in discussions about MUS. Importantly, it may act as a barrier to diagnosis of true somatoform disorders, which, according to the DSM-IV and the ICD-10, are required to be medically unexplained to be considered for the diagnosis, (213) entrenching mind-body dualism by implying mutual exclusivity between ‘medical’ symptoms and somatoform symptoms that this effectively locates in the mind. Those with somatoform symptoms may suffer from protracted medical investigations to ‘rule out’ a medical cause, when they would be better served by addressing the symptoms themselves and their causes.

In theory, it may be possible to distinguish between MUS and psychogenic symptoms or somatization in many cases through the diagnostic criteria for ‘somatic symptoms and related disorders’ in the DSM-5. The fifth edition of the DSM included modified criteria for somatization disorder in order to eliminate the conditions that the symptoms had to be medically unexplained or disproportionate to what would be expected with a related general medical condition, and specified that those with somatic symptom disorder had to have disproportionate and persistent thoughts about the severity of the symptoms, and high levels of anxiety and energy devoted to these symptoms or health concerns. (52,214) In practice and in research, however, somatization has been operationalized in ways that overlap substantially with MUS, describing a pattern of illness behaviour and generally an associated “clinical presentation, in which somatic symptoms are presented to the exclusion or eclipse of emotional distress and social problems.” (79) Often, MUS are assumed to be psychogenic in nature, in the absence of evidence to support this and without systematic ways of distinguishing symptoms that may be attributed to psychological distress from those that cannot, with the understanding that a true distinction between psychological and physical symptoms is based on a false notion of Cartesian dualism in which the mind and body can be clearly separated. In patients with MUS, a psychiatric diagnosis given too quickly based on negative criteria, that is to say the absence of causal pathology explaining the illness, prematurely closes biomedical investigation, risking missing a harmful diagnose and offering a poorly supported and stigmatizing diagnosis that is not helpful in guiding treatment or management of symptoms. Attributing the symptoms to an untestable psychogenic cause frees the physician from any responsibility to explain or defend diagnostic conclusions or treatments. Functional somatic syndromes are speculative explanatory models at best (82), and providing these labels without due investigation and explanation comprises a repudiation of professional responsibility of physicians to appropriately investigate patient's symptoms. This represents an inadequate collection of data from patients, focusing on the biomedical and objectifiable above all else, and failing to integrate the patient's situation and context, fundamental to the relationship-model of family medicine and a patient-centered care approach. (19,170)

As reviewed in Chapter 1, many physicians believe that patients with MUS have difficulty appropriately processing their emotions and have dysfunctional perceptions of bodily experiences, (51) despite the evidence that many patients with MUS show no evidence of emotional disorders (215) and may discuss their negative emotions spontaneously, with some patients introducing the connection between symptoms and emotions themselves in the consultation. (216) Without a clear distinction between symptoms that are medically unexplained and those which may be medically unexplained but can be attributed to psychogenic processes both in theory and in practice, communication about symptoms being medically unexplained may inadvertently imply psychogenic causation. The concept of hysteria as the conversion of distress into physical dysfunction (76) was adopted to "patch up" the inadequacy of the biomedical model that assumes a hierarchical connection between root physical causes and mental epiphenomena. (15) Expressions of distress that are perceived as 'hysterical' are considered to be psychodynamically less evolved and more regressive than more explicit expressions of psychological distress. (86) Hysteria, constructed by men to describe and caricature women and their afflictions that were deemed intractable biomedically, lives on under a variety of names, notably somatization or somatoform disorder, which repackaged the concept so that patients would be less inclined to resent and resist the diagnosis. (48,86,87) It is no wonder that terms such as somatoform disorder are so poorly accepted by patients. (61)

vi. Diagnosing Medically Unexplained Symptoms

Numerous articles investigate the acceptability of terms to describe symptoms that are medically unexplained, (58,61,63,64) all coming to different conclusions, but generally finding that labels that refer to the physical nature symptoms are more accepted by patients. (61,63) Patients provide several reasons for the advantages and disadvantages of each label, for example, MUS has been identified as frustrating, belittling and as "[d]octors code for 'all in your head' or fictional problems." (63) Despite the apparent neutrality and agnosticism of some of these terms, many are poorly accepted by patients, perceived as invalidating and stigmatizing.

Starcevic argues that any of the terms may be seen as pejorative by patients and as implying psychogenic causation, and that it is "unrealistic to expect patients to 'like' their own diagnoses: why should they like diagnoses of conditions that are responsible for so much of their suffering?" (217) He goes on to argue that there will never be diagnostic labels that have no potential of being misinterpreted or misused, and that it is futile to aspire to complete etiological neutrality and total acceptability to patients in choosing terminology in the area of MUS and somatoform disorders. (217) I would further this argument by positing that the clinical conditions in which these terms are used, which often neglect to explore patients' psychosocial situation, the conflation of uncertainty about the nature of the symptoms with implied psychiatric causation, and the origins of the concept of somatization and related disorders in hysteria mean that any terminology used to label the symptoms can be seen as stigmatizing, implying psychogenic causation, and invalidating to patients. This is less so due to the specific term employed; though that may contribute when terms that are explicitly stigmatizing and patient-blaming are used, and more a result of the interacting elements just described.

This is ethically relevant as it creates a situation in which labelling the symptoms without undermining the patient's authority on their experience may be virtually impossible, which complicates care for patients in which labelling of symptoms may be one way of offering the explanation that they so desire. (49,116,118–120,122,124,126,132) Further, as many of these labels are poorly perceived by at least some patients, attributing a label to a patient without an effort to ascertain how they perceive the label may be confusing, imply that the symptoms are made up, be perceived as humouring them, or evoke fear or hopelessness, (63) which may all exacerbate worries about symptoms or even contribute to a need to perform the sick role to become a ‘credible’ patient, (44) in the quest for care that addresses their needs and concerns.

Labels intended to express the unexplained nature of the symptoms may either directly or indirectly imply psychogenic causation, typically without sufficient support for this implication; simultaneously undermining the patient’s authority on their illness while absolving medicine of any responsibility to manage the symptoms, shifting responsibility for both cause and management onto the patient, effectively blaming them without resolving uncertainty and with the added stigma of implied psychogenic causation.

In addition to signaling a lack of diagnostic clarity, labels such as MUS name a diagnosis in the category of psychiatry, conflating uncertainty, lack of clear causal explanation for the symptoms, with certainty about psychological causes for symptoms. (175) While the mechanisms of MUS are not clear, the labelling of these symptoms often entrenches unfalsifiable pseudoscientific constructs of MUS and somatoform disorders (82) and undue implications about the psychogenic nature of the symptoms. While the *prima facie* problem of MUS from the medical perspective is an epistemological one of incomplete understanding of the symptoms, treating this uncertainty as indicative of psychiatric etiology is harmful and stigmatizing. O’Leary argues that this conflation as well as guidelines on cases of diagnostic uncertainty drive a focus on the goal of avoiding unnecessary medical care, with a lack of concern about avoiding error in psychogenic diagnosis, contributing to a tendency to overtest, overtreat and overdiagnose, (175) which will be explored in the last part (vii) of this section.

Despite the aforementioned problems with the diagnostic labels for MUS, there remain compelling arguments for labelling symptoms, in particular, for diagnoses that render the illness intelligible to the patient and the physician. Many of the diagnoses for MUS are non-explanatory, including various syndrome diagnoses such as chronic fatigue syndrome and Gulf War illness. There is debate about the validity of these labels as representative of distinct entities, (218) and suggestions for redefining MUS as one syndrome called “bodily distress syndrome”. (219) Additionally, there is a growing body of literature exploring explanatory mechanisms for MUS, (76,77) though these are currently theoretical and not applicable to the individual MUS patient, given the impossibility of determining all the factors contributing to their symptoms. Without engaging in the debate about the etiology and symptom overlap of MUS syndromes, I contend that explanatory labels are favourable to non-explanatory ones, such as syndrome diagnoses, and that explanatory pluralism in diagnosing MUS allows for the most accurate, efficient, and acceptable symptom explanations, as argued by Cournoyea and Kennedy. (220)

It is clear that patients seek medical care for their symptoms in large part because they wish to understand them, to have an explanation. This is consistent with the importance of meaning-making and understanding as therapeutically beneficial, potentially alleviating patients' distress (104) and the explanation of symptoms as an important intervention for MUS patients, (77) and may be why patients consider multiple, complex and fluid explanations (65–67,97) and remain unsatisfied with these. (97) Syndromic diagnoses can be used pragmatically to justify stopping investigations into the cause of the patient's illness. (220) Stopping investigation is inevitable and necessary, though when exactly is unclear, however this approach seems like an attempt to 'shut the patient up'. While MUS and related labels or syndromic diagnoses allow patients to build communities and networks to share their experiences and to advocate for themselves, such as is common with fibromyalgia (221) these may also drive harmful medicalization and reinforce conflict between patients and their physicians. (222) These labels allow for solidarity and support between patients, which may confer important psychosocial benefits, but they do not attempt to address the symptoms themselves, and likely contribute to driving patients away from allopathic medicine and evidence-based practice, worsening distrust in medicine as it has largely failed these patients.

Explanatory diagnoses may confer some benefit to patients by answering the question of why a patient has a given set of symptoms. With MUS, this explanation is not a clear physiological explanation, though considering the interindividual variability in the experience of symptoms medically explained by disease, explanatory pluralism is a relevant approach for more than just MUS, (223) allowing for consideration of all the relevant factors contributing to a patient's illness experience. A causal explanatory pluralistic approach to MUS allows us to understand why a patient is experiencing symptoms. It considers their context, their own concerns, and attempts to answer the important 'why' question through several, interacting responses not offering a single, clear etiology, but various causal factors and how they might contribute, (220) consistent with a PCC approach. It can be similar to the hypothetical explanations offered by physicians, though should necessarily engage with patients' own explanations, concerns, and lived context in order to be accurate and effective. Causal explanations can provide patients with structures to understand their suffering, from which they may glean epistemic and therapeutic benefits. (220) These explanations are consistent with a phenomenological approach, engaging with the patients' experiences and attempting to interpret them (17) in a way that considers patients' expertise in their own suffering and the state of medical knowledge. These explanations can be pragmatic and therapeutic, guiding the path to addressing the symptoms' relevant causal factors.

Necessary in the discussion of diagnosis of MUS are the risk-benefit assessments that must be made in decisions about diagnostic labels. Ideally, a diagnosis is a biomedical causal explanation which posits a physiological cause for the symptoms and guides treatment of the causal process. While this is not possible in the case of MUS, causal explanations are attainable and likely more appropriate and beneficial than syndrome diagnoses. This being said, there are other relevant considerations in the weighing of benefits and harms of diagnosing MUS.

GPs report balancing unwarranted medical accuracy and anticipated harmful diagnostic consequences in the search for a diagnostic category that would yield acceptable results without rendering them a liar in the process. (224) With any diagnosis, the clinical, economic, social and psychological consequences of the label employed must be considered: a good diagnosis should generate good, or at least avoid harmful outcomes. (224) With MUS, it is relevant to examine the benefits and harms of a diagnosis at the individual level. While it may be virtually impossible to quantify these explicitly, it is likely to be beneficial to patients to consider their concerns about their symptoms and their perceptions of labels in the process of determining how to address the symptoms, including determining the utility of a diagnosis and what diagnosis may be most helpful to the patient in making sense of the symptoms. Many of the challenges with diagnosing MUS and the approaches that are commonly taken are consistent with the evidence expounded in the second chapter, which made it explicit that many PCPs do not fully explore patients worries, desires for care, and concerns about their symptoms.

It is not clear that patients with MUS as a population benefit with any particular MUS label, especially given that perceptions of these labels vary between patients and over time. (217)

While there may be substantial syndrome overlap between various MUS syndromes, (218) reducing these all to one diagnosis offers little benefit in terms of explanation, management or treatment, and likely will exacerbate the label acceptability problem outlined by Starcevic. (217) When MUS labels do not lead to care pathways to address the symptoms, and patients' concerns remain unexplored and unaddressed, it is unlikely that they offer any benefit to patients. Though there is a broader ethical debate about diagnosis, honesty and health outcomes, this differs from ethical considerations in the diagnosis of MUS, as the process of selecting an appropriate diagnostic label is not a matter of choosing a diagnosis that represents an objective biomedical truth, nor a matter of harming a patient through the provision of a diagnosis that is necessarily life-altering. With MUS, selecting a diagnosis should be a matter of explanations that resonate with patients and do not create contradictions and conflict between the patient's reality, the physician, and the state of biomedicine, rather than a matter of establishing physiological causality for the symptoms. Of course, in medical systems in which obtaining care is contingent on the ability to pay or on access to insurance coverage, there is an argument for a pragmatic diagnostic choice that would grant the patient access to necessary care, while ensuring that it does not fall into the traps outlined previously which are endemic to care for patients with MUS.

vii. Overtreatment and Undertreatment

The essential question regarding the appropriate management of MUS is whether people who feel ill should be treated as healthy if there is no detectable evidence of disease. To respond affirmatively to this would be to reduce medicine to the enterprise of technical, mechanistic treatment of disease, blind to the patients' suffering, to their vulnerability, and to their needs. PCPs in particular operate within a relationship-based model of care, and ought to guide their medical decision making in a holistic clinical and moral sense, (170) considering each patient in a more complex, comprehensive contextual sense than other specialties would. PCPs are bound by the same code of ethics and professionalism as other physicians, notably continuing to provide services for the patients for whom they have accepted professional responsibility, and loyalty to use good clinical judgement in furthering the patient's best interests and goals of care, (169) in keeping with the ethical principles of justice, non-maleficence, beneficence, and protection of patients' autonomy.

In the context of communicating about MUS, the subject of this ethical analysis, the key questions are how to address MUS in communication with the patient, and how to decide what degree of certainty about the absence of rare disease is necessary. (225) As discussed, it is impossible to prove the absence of a causal pathology for MUS, but it can be reasoned that it is unlikely that all MUS are attributable to an underlying rare disease. There are risks of both under- and over-investigating, treating and diagnosing MUS, which are difficult to quantify and predict at the individual patient level. What can be assessed and modified in the patient-physician context, however, are the pressures that lead to overtesting and unnecessary intervention, such as perceived loss of control over the consultation and perceived patient pressure. Conflict and contest between patient and physician may lead to the PCP offering unnecessary somatic intervention. (103) Physician uncertainty may contribute as well. (51,125) Psychological disengagement from patients, negative attitudes about patients suspected to be somatising or to have MUS, (51,177) and the insinuation that symptoms are all 'in the patient's head' may prematurely close the consultation and result in under-investigation of symptoms. All of the discordant and challenging elements of the clinical consultation, which broadly share the theme of challenging the physician's authority and that place the credibility of the patient into question, can result in tangible and epistemic harms to the patient, through harmful and unnecessary treatments, and through the PCP's failure to listen to the patient's account of their illness, respectively. It is relevant to consider how both under- and over-treatment and investigation of MUS may lead to inequities in access to care and unjust allocation of healthcare resources. Underinvestigating symptoms suspected to be MUS, as a result of insufficient credibility and value accorded to the patient's testimony, may result in a misdiagnosis of MUS when the symptoms are in fact caused by an underlying pathology. This can preclude a patient from accessing care and can cause harms from unnecessarily protracted diagnostic processes.

Patients with MUS risk being overinvestigated and overtreated, owing to unnecessary somatic interventions and investigations that are believed to be offered in response to patient pressure, but may be in fact be justified by PCPs fear of missing a serious somatic diagnosis (204–206) as well as concern about undermining the patient's biomedical beliefs about their symptoms. (206) Patients whose illness testimonies are given less credibility, who are believed to not be appropriately interpreting their bodily sensations, or with whom physicians deem communication too challenging or burdensome may be disproportionally subject to these harms.

Conclusion

Existing paternalistic structures of the clinical encounter, and power dynamics that place the physician as the ultimate authority, entrenching the importance of disease and objective, biomedical data over the subjective, intangible experience of illness are especially problematic in the MUS consultation. The absence of identifiable evidence of disease, negative attitudes and beliefs about MUS patients, doubt about the patient's authority to understand, interpret, and convey their illness experience accurately, and false beliefs that the absence of evidence for a biomedical cause for one's suffering indicates the absence of cause altogether, all contribute to the epistemic injustice faced by patients with MUS, and the additional harms and related ethical challenges explored in the previous section. Rather than viewing the MUS patient's account of their illness as a misinterpretation of their bodily experiences, an inconvenient and frustrating contradiction to the lack of biomedical evidence for disease, consider that eliciting and clarifying the disruption and distress the patient is experiencing may be a constructive, effective and informative way forward, collaboratively making sense of the patient's experience to the benefit of the patient and the patient-physician relationship, without compromising the integrity of evidence-based practice.

Chapter 4: Envisioning More Effective & Ethical Explanations for Medically Unexplained Symptoms

Introduction

The approaches employed by PCPs to address MUS are generally well-intended, though they rely on the epistemic privilege of the physician as arbiter of the clinical consultation and as expert on biomedicine and physiology, and they minimize or even negate the patient's illness experience. Communication surrounding MUS often relies on the assumption that the patient will be relieved and their suffering alleviated when they are informed that their symptoms are not medically explained, as though the absence of evidence of disease is the evidence of absence, and as though informing them of this absence should alleviate the symptoms themselves. Patients with MUS are particularly subject to epistemic injustice in the discounting of their illness narrative and in the implication that they are misinterpreting their bodily sensations. Likewise, there is a lack of understanding of how to ethically and effectively communicate with patients who have symptoms that are medically unexplained.

This concluding chapter offers an evidence-informed, ethical approach to communicating about MUS founded in the primacy of the patient's epistemic authority over their illness, the need for explanatory, constructive communication about MUS, making use of the physicians' biomedical expertise. While clinicians, and physicians in particular, have a unique ability and extensive knowledge base that allows them to scrutinise constellations of symptoms and draw meaning from them, using evidence from physical examinations and medical investigations, they are often limited by the epistemic injustice in contemporary healthcare practice that they contribute to entrenching. This may be attributed to clinicians' reluctance to recognize, discuss, or acknowledge MUS in any capacity other than the lack of evidence for a medical explanation, (82) and faulty assumptions that lack of evidence for disease can disprove the experience of illness, undermining the patient's experience with necessarily inconclusive or limited evidence.

The communication strategy outlined in this chapter supplements the patient-centered clinical method with novel approaches to conceptualize pain, illness, and illness explanations. The patient-centered clinical method, which seeks to attain an integrated understanding synthesis of disease, health and the illness experience unique for each patient (19) requires that the physician let go of their hierarchical power over the patient in the consultation, thereby empowering the patient and reshaping the patient-physician relationship based on this shift in power. It also demands a balance between the subjective and objective, (19) bringing together the patient's bodily experience and their interpretations and meaning-making with the biomedical evidence accrued through examination and investigation. In large part, the problems in the MUS consultation stem from the mistaken assumption that the absence of biomedical evidence of an underlying explanatory pathology disproves the experience of the patient.

This chapter does not elaborate on the patient-centered clinical method itself, which has been written about extensively and is widely recognized, though often criticized for being taken up only in name and not practice, and for not offering specific approaches or conceptual clarity, (226–230) though it will in part address the latter argument. PCC for patients with MUS requires concrete methods to conceptualize pain, illness, and illness explanations.

Pain is conceptualized according to Peter Stilwell and Katherine Harman's enactive approach, which constructs pain as an embodied, embedded, enacted, emotive, and extended (or 5E) process. This approach conceptualizes pain as "a relational and emergent process of sense-making through a lived body that is inseparable from the world that we shape and that shapes us." (18) Thus, the meaning-making process is integrated into the pain experience itself, and the problematic fragmentation and reductionism of biomedical and biopsychosocial constructs of pain are avoided. This approach borrows from phenomenology and cognitive sciences, and is well complemented by Havi Carel's phenomenological toolkit, which offers a resource to "help patients to philosophically examine their illness, its impact on their life, and its meaning." (165) Employing these resources and ways of conceptualizing pain and illness, the PCP can work alongside the patient, throughout the patient-physician relationship, to make meaning of the patient's illness experience in a way that affords them agency over their body and their symptoms. Monica Greco's creative accountability and speculative pragmatism (101) and Cournoyea and Kennedy's causal explanatory pluralistic approach (220) to addressing the challenge of explaining MUS are used to guide this patient-centered method to caring for the patient with MUS, conceiving of explanations as speculative pragmatic wagers whose truths lie in their clinical effects, rather than seeking representational, objective truths. (101)

This integrated clinical method does not aim to disregard nor deny the absence of evidence for an underlying explanatory pathology in the case of MUS. Rather, it aims to re-center the patient's experience of illness to address what is fundamentally unsettling and disruptive, benefitting from the relational and long-term quality of the primary care patient-physician relationship. This chapter will first provide explanations of each of these frameworks, then will conceptualize their integration into a patient-centered primary care practice.

Part A: An Enactive Approach to Pain

Stilwell and Harman's enactive approach to pain borrows from phenomenology and the cognitive sciences and Gallagher's '4E' conception of the mind, which proposes that cognition is i) embodied, ii) embedded, iii) enacted, and iv) extended. (231) Their enactivist conception of pain adds v) emotive to these four Es, proposing that this means of understanding pain is promising as it "does not commit the mereological fallacy, is not dualistic, appreciates the first-person experience of pain, and avoids the trichotomization or dichotomization of pain that is common when clinicians apply the biopsychosocial model." (18) as well as having a strong theoretical foundation and accounting for theories of perception not considered in other theories of pain. (18) In this section, this 5E approach is briefly explored[14].

i. Embodied

The first of the 5Es is embodied, representing one's active physical, temporal and social immersion as making meaningful experience possible, (232) viewing the physical body and the subjectively lived body (Heidegger's being-in-the-world) as inseparable and concomitantly necessary when comprehensively exploring pain and embodiment. The body-as-object view of biomedicine is seen as affecting and setting limits on the experience and interpretation of the lived body. (4) This phenomenological, strong conception of embodiment (231) views perception as an active process, the body as directed to the world through Merleau-Ponty's motor intentionality (233) and cognition as happening not just in the brain, rather in a feedback loop between "the central nervous system *and* the non-neural body, bodily activity, autonomic and peripheral systems, and relations with the environment." (18) These processes and relationships

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[14] This overview endeavours to preserve the nuance of the original paper, but some is likely to be lost in the interest of brevity. For a more comprehensive and thorough explanation, see Stilwell and Harman's article. (18)

are inseparable, interacting, and inextricable from the environment, consistent with a phenomenological approach to illness, which places the embodied experience and the interpretations of the lived body at the fore.

ii. Embedded

From embodiment comes embeddedness, the phenomenon of being situated in an environment, with perceived changes in that environment seen in relation to potential for action as afforded and constrained by the given environment. (18) This is to say that our interpretations of experienced situations are made based on past experiences (background), the current context and what is subjectively perceived to be possible within the given environment. The body and world are thus inseparable, and bodily feelings are not internal to the body but the experiences of the relationship between the body and the world. Pain, understood via embeddedness, is thus shaped by the situation and environment, which "can embed a sense of threat or safety, worsening or dampening pain". (18) In persons with chronic pain, engagement with the world engenders "ongoing threat to the integrity of the body and concern regarding triggering more pain." (18) Some environments will generate more pain than others. This embeddedness pertains to predictive processing, which is based on the idea that our past experiences and how we have processed these create our perceptions of what sensation, movement, or event will occur next. The sensations (such as pain or other symptoms) we experience are thus in large part informed by the priors and expectations determined by our previous experiences in a given environment or with a particular movement or activity. Pain is always embedded, and situational context must always be considered.

iii. Enacted

The enacted quality of pain describes the way it is brought forth through an organism's embodied interactions with the world, responding dynamically to environmental changes based on past experiences, learnt response patterns, and evolutionary and developmental processes. (234,235) Importantly, enactivism views meaning as a relational process of sense-making, which, in the context of pain, means that the ongoing presence of threat (i.e. in the form of particular environments) triggers the persistence of the perception of pain. The process of sense-making occurs in the finding and creating of meaning and significance in the world, and this represents coupling of people with their environments. Participatory sense-making, as defined by De Jaegher and Di Paolo, (236) occurs when “people engage in interactions that produce meaning or significance that could not be produced by either individual alone.” (18) Thus, the sense-making regarding pain or other symptoms, medically explained or not, is particularly relevant within the patient-practitioner relationship, and this meaning making, enactive process is part of the experience of pain itself, in its role in the environment and the development of an understanding of the experience that shapes the pain experience.

iv. Emotive

The emotive quality of pain is coupled with cognition, and focuses on affective framing and fear of pain. Affective framing concerns the real and perceived threats of the person in pain, who is “stuck in a liminal state and trying to adapt through enacting pain/emotion.” Stilwell and Harman cite studies connecting fear, anxiety and catastrophizing to the maintenance and amplification of pain, as well as how perception and fear of tissue damage amplify pain intensity (18). The enactive-emotive process of conceptualizing the meaning of pain is impacted by “verbal suggestions, visual cues, and other contextual factors [which] combine with past experience, knowledge, and attention/expectations to form meaning”. (18) These factors may be largely predetermined prior to the patient seeking care from their physician for their symptoms, and meaning may not be necessarily easily reconceptualized, but there remains an important role for the physician in the suggestions and explanations they offer about patients’ symptoms.

v. Extended

The fifth E, extended, describes the notion of the extended mind, wherein the biological aspects of bodily life, objects in the environment, including tools (such as pens and phones) and institutions are coupled with the person, (237) who is inseparable from the world. Patients are coupled with clinics and society, which generate scaffolding for their pain experience, (237) shaping their pain-related behaviours and narratives about their pain and their body as it relates to their environment. Thus, it is important to consider the nocebo effects of certain environments and healthcare interactions, which might contribute to amplification and maintenance of pain. (238) Pain is a relational process of sense-making, and while it is experienced from a first-person perspective, it can be viewed as a relational process of meaning-making in which the environment and other people, notably clinicians, play an important part. (18)

Considering Stilwell and Harman's model, (18) which provides a non-dualistic conception of pain that acknowledges the existence of possible pathoanatomical causes but does not rely on these in the process of pain generation, it is easy to see how the patient's environment and interactions with healthcare providers and systems are part of the meaning- and sense-making process of pain. Physicians play an important role in shaping beliefs about pain, notably, beliefs that back pain (of which 90-99% of cases have no readily identifiable pathoanatomical driver to explain the pain experience (18,70)) is due to the body being like a 'broken machine' and that one's pain was immutable and permanent originated from healthcare providers. (239) Given their powerful role in the meaning-making process, their ability to generate negative narratives about pain which can have nocebic effects, amplifying and maintaining the pain experience, it is crucial that their communication about symptoms is informed by an understanding of the way in which communication and explanation of symptoms can act as scaffolding for the experience of pain itself.

Part B: Pragmatic and Effective Explanations

Physicians often play a role in the co-production of somatization, fostering an iatrogenic dimension to the consultation by neglecting to address the patient's concerns about their symptoms and by effectively creating a situation in which the patient must fight to have their symptoms addressed and their illness experience attended to. Much of this iatrogenic process appears to stem from the efforts patients make in an attempt to demonstrate the legitimacy of their symptoms and engage their doctors, which doctors often respond to by offering unnecessary somatic intervention. (45) This needn't be the case. Given physicians' ability to contribute to somatization and their important role in shaping beliefs and expectations about symptoms, and their formative contributions to the embedded, enactive, emotive and extended elements and qualities of each pain experience, they are well positioned to influence these in more positive ways. Importantly, the PCP must see their role as one of fostering environments, beliefs, and situations that contribute to meaning-making in ways that are adaptive and confer agency and positive expectations to the patient with MUS. This is by no means a suggestion that the PCP can make the patient think away their pain, or that pain is all in the (disembodied) mind. Rather, this approach recognizes the complex, inextricable coupling of any symptom experience to the environment and the clinician's importance within the environment and in contextualizing experiences, especially through the provision of a diagnosis or explanation for the symptoms, an instrumental part of the sense-making process.

While many of the approaches PCPs employ to communicate about MUS are ineffective and contribute to discordance with the patient, a few of the consultation styles and communication strategies consider various explanations for the symptoms and the patient's perspective on these. These include a consultation styled dubbed 'following various paths' which is characterized by a dialogue with the patient in which various (physical, psychological and social) explanations for the symptoms are considered, negotiating towards a shared understanding of the meaning of the symptoms. (138) 'Deliberation' has also been identified as a successful approach, in which both the PCP and the patient contribute ideas and work together towards a mutually acceptable explanation. (139) A 'collaboration'-style consultation may also be effective, in which both parties strive towards common ground and shared understanding. (103) Effective explanations are often those that include tangible mechanisms that emerge from discussion with the patient and includes links between physical and psychosocial factors. (80)

The lack of identifiable pathological explanation for the symptoms requires a different approach to explaining them. Many of the strategies employed to explain the symptoms or reassure the patient reflect an apparent belief that the absence of identifiable pathology to explain the symptoms can be leveraged as evidence that the symptoms are insignificant or illegitimate, and that this approach can contribute to resolving the symptoms, when in fact it appears to have the opposite effect. Rather than the PCP attempting to minimize the symptoms (ineffectively, without addressing the patient's concerns) or offering hypothetical explanations (that may be plausible but are not definitive and do not resonate with the patient), explanations for MUS must be cognizant of their formative role in shaping the symptoms themselves. Kirmayer describes this as explanations offering a "prospective, proactive and prescriptive" truth, (197) and Greco envisions this truth as part of an explanation that shapes the embodied experience of the patient towards an alternative future in which symptoms can resolve. (101) The co-

construction of an appropriate explanation or normalization that provides a satisfactory representation of illness can in fact provide relief, (101) consistent with the 5E understanding of pain and our understanding of the importance of explanations, which can be therapeutic in their conferring of a cogent understanding of the symptoms.

Greco (101) and Cournoyea and Kennedy (220) propose complimentary methodologies for creating explanatory diagnoses for MUS. Cournoyea and Kennedy advocate for causal explanatory pluralism, demonstrating that explanatory diagnoses are preferable to non-explanatory syndromic diagnoses as they confer both epistemic and therapeutic benefits to patient and physician. (220) They argue that explanatory diagnoses are preferable over syndromic diagnoses for MUS, which fail to offer an explanation, and as a result, do not offer prognosis nor guide treatment. Explanatory diagnoses, while not possible within biomedical reductionism for MUS, are preferable over the requirement of negative criteria to make syndrome diagnoses, which require the ruling out of all possible alternative diagnoses (in addition to the presence of symptoms consistent with the syndromic diagnosis in question). The syndromic diagnoses are often pragmatic in that they serve to end the investigation process. Cournoyea and Kennedy argue that the pragmatic gain of these diagnoses is outweighed by epistemic and therapeutic losses, and that MUS and other syndromic diagnoses serve as "optimistic placeholders for future causal explanations." (220) Explanatory diagnoses, on the contrary, needn't be completely (objectifiably) accurate to provide understanding to both patient and clinician and render a phenomenon (the symptoms) intelligible to both parties. (241) The pathophysiological *why* is unavailable in the case of MUS, and it is the understanding of this *why* (rather than the *that* of the presence of symptoms offered by non-explanatory diagnoses) that confers the aforementioned benefits, which has been corroborated by a qualitative literature review on explanatory models for MUS (77) and is supported by the emphasis patients place on seeking an understanding for their symptoms in primary care.

Cournoyea and Kennedy (220) argue for a version of explanatory pluralism based on a methodology outlined by De Vreese *et al*. (241) Explanatory pluralism is the perspective "that the best form and level of explanation depends on the kind of question one seeks to answer […]" and that often more than one form and level of explanation is needed. (241) While the medical sciences would benefit from this explanatory methodology, they argue, medical research and practice are currently too reductive and do not fully allow for true explanatory pluralism. (241) By asking questions about why a particular patient developed a given set of symptoms, one can begin to conceive of a number of reasonably plausible explanations for the symptoms that pertain to the various contexts relevant to the patient and a number of different levels (ranging from the biochemical to the sociocultural and societal). This approach eschews the reductionism and dualism of the biomedical or biopsychosocial model, and importantly would avoid the stigmatizing process by which psychiatric diagnoses or dismissive normalizations are offered for MUS without due exploration of symptoms. The communication required to ask and answer all of these *why* questions would be patient-centered and consistent with the 5E approach to pain, which considers the complexity of context, environment, and past experiences in the generation of pain and as part of the experience of pain itself. This is to say that the patient plays an important, central role in the asking of the questions, allowing them to raise factors they believe to be relevant to their symptoms, and in the answering of these questions, working with the physician in a collaborative, deliberative way to attain an explanation that is acceptable to both parties. The biomedical reasoning processes that physicians engage in when making biomedical diagnoses are not possible in the strict biomedical sense for MUS, however this approach would offer a similar type of systematic reasoning and investigation of symptoms and their causes. The objects of the investigation would emerge primarily from communication with the patient, rather than from biomedical investigations (which would also play a role, however less prominent).

Greco argues for creative accountability in the explanations provided for MUS, arguing that the problem of explanation should be recast from the need for a “representational, objective truth on the basis of which treatment of one kind or another should follow,” towards a pragmatic wager “whose truth lies in the quality of its clinical effects.” (101) This is characterized as speculative pragmatism, “a wager on the unfinishedness of the present, […] making thought *creative of an alternative future* by producing an inventive response to an impending problem and by putting experience to the test of its own *becoming*”. (242) This approach endeavours the patient and the physician to work towards an explanation that is pragmatic and constructive. Pragmatic, in this context, refers to the ability of the explanation to guide the patient and the physician towards a future in which the embodied experience of the patient can be shaped towards new, desirable possibilities. These possibilities would be defined according to the goals of care of the patient in question, a crucial element of the patient-centered clinical method. (19) This contrasts with the intended pragmatic value of brain-based explanations for MUS[15], which attempt to purchase legitimacy on a piecemeal basis, while entrenching reductionist mind/body dichotomies that systemically contribute to the experience and predicament of MUS. (101,243) Pragmatic explanations should be "prospective, proactive and prescriptive," (197) leading towards a better outcome in a way that can be defined by and with the patient, and acted upon.

Constructive here refers to the use of the explanation towards the patient's expectations and goals of care. In following the enactive approach to pain, (18) it is understood that the environment in which the patient is embedded affords certain perceived possibilities and constraints, and that the process of sense-making is inextricably coupled with the environment and the significance attributed to interactions within the given environment. Approaching explanations in this way acknowledges the importance of the clinician in affording possibilities and defining constraints, and in the experience of symptoms themselves. The co-construction of an explanation for symptoms must include the patient in the process of understanding the *why* of the symptoms, (220) creating an explanatory pluralistic explanation, that must be understood as prescriptive and formative, (101) as ultimately integrated into the unfinished, ongoing experience of the symptoms themselves. The explanation for the symptoms becomes integrated into the symptom experience, should be empowering and devoid of judgement or blame, and should evolve alongside the patient's experience of the symptoms, made possible by the relationship-based, long-term nature of the primary care patient-physician relationship.

This approach to explanation could be criticized for not being biomedically accurate, or for being too hypothetical, not sufficiently grounded in evidence. These criticisms would neglect the fact that the symptoms are, by definition, not accounted for by biomedicine; currently impossible to explain, a limits case of reductionism and of EBM, (20–22) and that alternative explanations and diagnoses are often contested, not strongly supported by the evidence base

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[15] Those that rely on findings of unclear relevance on MRIs or PET scans as evidence of abnormalities causing particular contested conditions.

and are not based in the evidence and information about the patient in question. These criticisms neglect the necessary hypothesizing and generalizing required to make any diagnosis, and the fact that alternative diagnoses rely on negative criteria (the absence of evidence) and on fallible, mutable constructs of contested medical conditions and syndromic diagnoses.

More relevant criticisms of these explanations would rest in the argument that patients and physicians might be unprepared for the collaborative, deliberative, and likely challenging process of conceiving of these explanations. PCPs, known to have limited time with patients and to be frustrated with patients with MUS, may not be prepared to devote the energy and time to the ongoing discussion and the open-ended, uncertain and conceptual nature of these symptom explanations. They may struggle with the lack of identifiable pathology and be uncomfortable with the relinquishing of authority that this form of explanation and style of consultation entails. Patients, for their part, may expect that the physician can offer something more definitive; simpler to identify and define, easier and more predictable to manage and treat. Addressing these criticisms, while acknowledging that it is impossible to do so in a way that would satisfy all patients and all clinicians, is the task of the next section, wherein Havi Carel's phenomenological toolkit, which enables and empowers patients to thematize and examine their illness to participate in the phenomenological process of reflecting on their illness, will be presented.

For the PCP's part, it is necessary to acknowledge that institutional and systemic factors make adoption of this method and of patient-centered approaches more generally quite challenging. Many healthcare systems prioritize the number of patient visits over the quality or duration of these visits, and diagnoses that are formally recognized may be required for the purposes of physician compensation or for the patient to access health insurance coverage. These important issues require a fundamental paradigm shift in medicine that reflects the already acknowledged necessity of a patient-centered clinical method, and the shortcomings of biomedicine and problematic nature of for-profit healthcare systems. Further, there is a need to acknowledge and address existing biases in medicine about all that which is not objectifiable in the biomedical sense. These comprise an element of the particular burden of epistemic injustice faced by patients with MUS, as detailed in the previous chapter, which accounts for, in part, biases against patients with MUS that may act as barriers to the adoption of these methodologies and approaches to care. PCPs admit to psychologically disengaging from their patients and many decline training to improve their psychosocial skills with these patients, (177) despite evidence that training to improve communication with patients with MUS can improve the interviewing and information sharing skills of physicians. (244) Perhaps teaching patients to make sense of their symptoms by thematizing them and reflecting on them using phenomenological concepts will improve clinicians' resistance to engage with these patients. Helping the patient form more coherent narratives about their symptoms may enable more constructive communication about symptoms in the consultation, though there is nonetheless work to be done on the part of many physicians who care for patients with MUS (and those with medically explained symptoms, as the methodologies outlined in this chapter can serve to improve care for all patients).

Part C: The Phenomenological Toolkit

Havi Carel's phenomenological toolkit offers a resource to "help patients to philosophically examine their illness, its impact on their life, and its meaning." (165) This toolkit provides approaches to view illness as a form of phenomenological reduction and examine it as altering the ill person's being in the world. It employs phenomenology as a way of reflecting on and thematizing illness that allows the ill person to make sense of the intrusion and way of being that is illness. Carel posits that patients' understanding of illness is restricted by biomedicine's focus on the physiological dysfunction, resulting in the experience of illness and the changes it brings remaining unacknowledged within clinical medicine. (165) Patients learn about their illness biomedically and often adopt this language in their discourse about their illness, which may lead to a lack of a true first-person understanding of their experience and of genuine attempts to make meaning of illness as they are living it. (165)

Phenomenology allows for the first-person exploration of the experience of illness, for an examination of the phenomena of bodily disruption. Toombs identifies essential characteristics of the experience of illness: the loss of wholeness and bodily integrity, loss of certainty, loss of control, loss of freedom to act, and loss of the familiar world. (166) To these, Carel adds three themes: changes to the experience of space and time, lost abilities, and adaptability. (165)

The phenomenological toolkit aims to offer a flexible individual tool to develop an understanding of one's illness through three steps: i) the phenomenological reduction, ii) thematizing illness, and iii) reviewing one's being in the world. (165) These three steps will be described and the particular relevance of each element of the toolkit to MUS will be highlighted.

i. Phenomenological Reduction

The experience of illness, in its disruptiveness, provides an opportunity to examine our conventional understandings and expectations of our life, and revaluate choices, routines and habits. Through illness, withdrawal from habitual ways of being becomes possible, and the patient can engage in phenomenological reduction, "a suspension of a 'natural attitude' of implicitly accepting the background sense of belonging to a world and various interpretive dogmas along with it." (165,245) This process of bracketing of the natural attitude towards illness shifts the focus away from the objective disease process and towards the experience of illness. (165) This is particularly necessary for patients with MUS, for which an underlying disease process is not identifiable. It draws attention instead towards the experience of illness, endeavouring to make sense of it and explore it as it is lived, rather than in reference to disease. This may enable patients with MUS to shift away from a focus on (the lack of) biomedical explanations, and if this phenomenological reduction and bracketing process is engaged in with the physician, it can help them reframe their attention towards the patient's experience, as well.

ii. Thematizing illness

From phenomenological reduction, illness can be thematized, or the "act of attending to a phenomenon, which makes particular aspects of it explicit. (166) This includes attending to the cognitive, emotional, moral or aesthetic aspects of a phenomenon and identifying the centrality (or peripheral nature) of the symptoms to the patient's life. Often illnesses are thematized according to how the symptoms match up with objectifiable biomedical evidence and diagnostic findings, but this needn't be the case, and in fact, engaging in this process with MUS should involve moving away from this prescriptivism, towards a descriptive mode. (165) Thematizing can be complex and consider a variety of perspectives, and these can foster an understanding of different dimensions of the illness experience, moving away from the reductive biomedical understanding, towards a complex, evolving view of illness as the patient experiences it and understands and constructs meaning from their experience.

iii. Reviewing one’s being in the world

The third and final step of the toolkit takes the newly thematized and understood illness and examines how it changes one’s being in the world, which is made up of one’s biological entity, the person, their environment and meaningful connections. (246) This process involves examining the pervasive effects of illness on one’s existence, on their interactions with the environment and with others, on their sense of place, on meanings and norms, and on habits and people that make up their world. (165) Reviewing one’s being in the world as the third and final step in this toolkit allows for the development of a comprehensive account of illness.

While the toolkit defines three steps to engage in a phenomenological analysis of one’s experience of illness, to develop an understanding of illness based in the experience as it is lived, rather than one centred around biomedical signs and pathology, or rather the lack thereof, it remains unclear how it would be best implemented in practice. Carel suggests workshops for patients to use the tool in groups, and questions whether healthcare providers would be included in these workshops, and whether this approach would be accessible to a wide variety of patients. (165) In the concluding section, an approach will be suggested, tying in phenomenology as a resource for patients with the enactive approach to pain and the reconceptualization of explanations for symptoms through causal explanatory pluralism and speculative pragmatism.

Part D: Effective, Enactive and Ethical Patient-Centered Explanations for MUS

Through the methodologies examined in the previous sections, a new approach to understanding and explaining MUS, central to communication about the symptoms, is offered. This approach consists of enabling the patient to explore their illness experience and construct meaning and a coherent understanding of their symptoms. Employing the approaches in the phenomenological toolkit, the patient can construct a coherent, satisfying narrative about their symptoms, which would serve not only to provide epistemic benefits in the understanding of their experience, but would allow them to engage with their PCP more constructively. The toolkit enables patients to make explicit the qualities of the symptoms that are the most salient to them, as well as their most significant worries and concerns. The phenomenological toolkit could be offered to patients in small group workshops but may also be effective if provided through teaching materials with guidance and some instruction from their healthcare provider.

The PCPs for their part must develop an understanding of the embodied, embedded, enacted, emotive and extended approach to pain, appreciating how the environment and the language they use in particular to discuss symptoms construct scaffolding and expectations that impact the symptoms themselves. In this way, the explanations they offer become part of the symptom experience. Thus, the communication that occurs regarding symptoms must be judicious in its use of language, ensuring to not foster beliefs that the symptoms are irresolvable or that the patient is helpless in the face of intractable symptoms. The co-creation of explanations for MUS must engage significantly with the patient's understanding of their illness, elucidated via the phenomenological toolkit, and must rely on this to generate plausible causal explanations for the symptoms. The explanations often will involve multiple levels of causation and varying degrees of certainty about these, and they can be updated over time as the patient's symptoms evolve and as different elements of the patient's life and the symptoms become more salient.

The patient, experiencing new symptoms, would raise these with their PCP, who would use the methods of patient centered medicine to elicit the patient's experience of the symptoms, asking questions to draw forth the most prominent elements of the illness experience. The FIFE acronym of patient-centered medicine—feelings, ideas, functions and expectations (19)—should be used to gain an understanding of the patient's unique illness experience. This understanding can be deepened and conceptualized in reference to the losses experienced in illness as described by Toombs (i.e., loss of wholeness and bodily integrity, loss of certainty, loss of control, loss of freedom to act, and loss of the familiar world, (166)) and the themes of illness described by Carel (i.e., changes to the experience of space and time, lost abilities, and adaptability. (165)) During this process, the PCP will perform the relevant biomedical investigations into the patient's symptoms. It is relevant and necessary to investigate how patient-centered clinical methods alter physicians' decision making in the investigation process, relative to less patient-centered methods, and how these bear on factors such as pre-test probability of the presence of certain conditions, and outcomes such as time to diagnosis in the case of medically explained symptoms. Additionally, it would be important to investigate how the PCP's initial suspicion of the patient experiencing MUS informs the patient-centeredness of their approach (there is already some evidence indicating that PCPs consult in a less patient-centered way with these patients (43)) as well as interrogating how early suspicion of MUS bears on the process of investigating symptoms (looking at this both qualitatively including examining cognitive biases, as well as quantitatively in terms of number and types of investigations and patient outcomes).

After the relevant, dangerous pathologies have been ruled out, or during this process if it is more complex and involves prolonged investigations, the patient should continue the phenomenological investigation of their symptoms embarked upon in the initial assessment. The PCP could provide them with the materials to engage in the methods of the phenomenological toolkit, choosing between group workshops, self-guided reading materials and workbooks, or a personalized approach with a specialist in this method, depending on what is available and preferable (as decided by patient and physician) for a given patient. Through the tools of this phenomenological examination of their illness experience, the patient could develop a cogent, personal and rich understanding of the disruption, loss, and changes they experience in illness.

In a subsequent appointment with their PCP, this understanding could be explored in an effort to deliberate, negotiate, and collaborate on a mutually acceptable explanation for the symptoms, approaches identified in the literature on primary care for MUS as acceptable to patients and PCPs alike, and effective in their inclusion of tangible mechanisms and their role in a coherent, concordant patient-physician relationship. (80,103,138,139) Explanations should emerge from a process of asking a series of 'why' questions to determine the causes for a patient's illness experience.

Asking and answering the 'why' questions serve to address the fundamental need of the patient to understand their illness. While biomedicine does not provide a clear explanation, this does not mean that the symptoms are 'all in the head' or nonexistent altogether. The process of asking and answering these 'why' questions should be guided by the most salient elements of the patient's illness experience, which have been clarified and brought to the fore through their phenomenological investigation of the symptoms. The goal of this process is attaining an explanatory diagnosis that draws from the patient's intimate, rich knowledge of their illness and how they experience it and the physician's understanding of pathophysiology and of the process of symptom generation. An explanatory diagnosis needn't be complete nor completely accurate to provide understanding to both patient and clinician and render a phenomenon (the illness) intelligible to both parties. (240) There may be some initial difficulty in resolving disagreements about symptom causes and precipitating factors, and in contending with the unavoidable uncertainty that is endemic in medicine. These difficulties could be resolved to a large extent through deliberation and negotiation.

Explanations should be pragmatic in the sense that they provide epistemic and therapeutic benefit to the patient, offering truth in the way they shape the illness experience, truth which “lies in the quality of its clinical effects.” (101) This is to say that the explanation should be understood as becoming integrated into the experience of the symptoms themselves, consistent with the 5E understanding of pain described by Stilwell and Harman. (18) Explanations can offer a “prospective, proactive and prescriptive” truth, (197) shaping the embodied experience of the patient towards a future in which they have agency over the symptoms. The co-construction of explanations for the symptoms should aspire to offer a satisfactory representation of illness, addressing the patient’s concerns and providing relief, consistent with our understanding of the importance of explanations, which can be therapeutic in their conferring of a cogent understanding of the symptoms.

The explanation should be pluralistic in the sense of offering reasonably plausible explanations for the symptoms that operate at a number of different levels (ranging from the biochemical to the sociocultural and societal), avoiding the reductionism of the biomedical model and the false dichotomy of biological versus psychological that is often constructed with MUS. The patient must play an important, central role in the asking of the questions, informed by their concerns and their rich understanding of their illness that has been clarified via phenomenology. The responses should embed a sense of safety, rather than threat, and serve to construct a scaffolding of understanding and causation that can empower the patient to accept, adapt, and cope with their symptoms, with the ongoing support of their PCP. Greco describes this as speculative pragmatism “a wager on the unfinishedness of the present, […] making thought creative of an alternative future by producing an inventive response to an impending problem and by putting experience to the test of its own becoming.” (242) The explanation for the symptoms should be conceived of as part of their treatment, as a core element of patient care, as the narrative constructed about ones illness comes to be part of the illness experience, and can guide the path towards a future of coping and resilience in face of illness, rather than worsening, iatrogenic and often intractable suffering and a sense of loss of control over one's body and one's life. Patients can define the outcomes they desire and wish to strive for and can work with their PCPs to shape their future in which these can be attained. Explanations should be enactive, producing meaning through interactions with the world (primarily with the clinician) that is empowering and that provides coherence and relief to the patient who is faced by the chaotic disruption that is illness.

This approach, which must be tested clinically, is supported by what patients with MUS indicate they desire and expect from their PCPs, as elaborated in detail in the second chapter, and consistent with the patient-centered care approach. It reimagines care for patients with MUS in a way that shifts the emphasis away from the (absence of) biomedical explanations, towards a more complex, constructive understanding of the symptoms, cognizant that the way symptoms are understood shapes the experience of the symptoms themselves. This approach seeks to resolve the conceptual problems of MUS, that is the absence of biomedical explanatory pathology, the lack of clarity about sufficient evidence to establish causation, the impossibility of proving a negative and the false dualism of 'real' versus psychological symptoms, as well as the communication challenges surrounding care for patients with MUS, and the related ethical issues that arise in the neglect for the patient's authority over their own experience. The physician nonetheless engages in their role as an interpreter of the language of bodily experiences, but the interpretation is a collaborative, patient-centered process, no longer limited by the inadequate framework applied to understanding MUS. (12,20) Causal explanatory pluralism and pragmatic prescriptive explanations subvert the inadequacy of reductive biomedical frameworks of understanding and employ phenomenology to reframe the explanations of medically unexplained symptoms to reflect the complexity and richness of the lived experience of illness. Through these approaches to constructing explanations for symptoms, the illnesses that biomedicine cannot account for can be reconceptualized for patients in ways that are empowering, health-promoting, and that provide patients with authority, agency and needed coherence over their fundamentally private and radically disruptive illness experience.

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