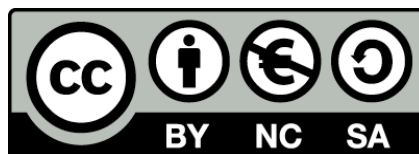




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Incongruent Views of Quality of Life between Patients and Physicians: A Mixed-Methods Enquiry

Alicia Georghiades



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Incongruent Views of Quality of Life between Patients and Physicians: A Mixed-

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Alicia Georghiades

Director: Dr. Francisco José Eiroa Orosa

Director: Dra. Anna María Accarino Garaventa

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To my family for their unconditional love.

To Alex for his continual support.

To all that I have met along the way,

Thank you for helping me on this journey.

The good physician treats the disease; the great physician treats the patient who has the disease.

William Osler

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List of abbreviations

CBT: Cognitive Behavioural Therapy

CD: Coeliac Disease

BCT: Behavioural Change Technique Taxonomy

BP: Bodily Pain

BSI-18: The Brief Symptom Inventory

COREQ: Consolidated Criteria for Reporting Qualitative Research

EPS: Epigastric Pain Syndrome

FD: Functional Dyspepsia

FGID: Functional Gastrointestinal Disorders

FSS: Functional Somatic Symptom

GH: General Health

GMD: Gastrointestinal Motor Disorders

GI: Gastrointestinal

GP: General Practitioner

HCP: Healthcare providers

H.Pylori: Helicobacter Pylori

HRQOL: Health-Related Quality of Life

IBD: Inflammatory Bowel Disease

IBS: Irritable Bowel Syndrome

IBS-QOL: Irritable Bowel Syndrome Quality of Life

IBS-SSS: Irritable Bowel Severity Scoring System

JARS-Qual: Journal Article Reporting Standards for Qualitative Research

KPS: Karnofsky Performance Status Scale

MH: Mental Health

MCM-III: Millon Clinical Multiaxial Inventory-III

MUS: Medically Unexplained Symptoms

PCC(s): Primary Care Centre(s)

PCPs: Primary Care Physicians

PDRQ-9: The Patient-Doctor Relationship Questionnaire

PDS: Postprandial Distress Syndrome

PHQ-4: Patient Health Questionnaire 4

PF: Physical functioning

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
guidelines

PROMIS: Patient-Reported Outcomes Measurement Information System

QOL: Quality of Life

RE: Role Emotional

RP: Role Physical

RPM: Remote Patient Monitoring

SF-12: The Short-Form Health Survey

SF-36: 36-item Short-Form Health Survey

SF: Social Functioning

SPSS: Statistical Package for the Social Sciences

VT: Vitality

Abstract

Functional gastrointestinal disorders (FGIDs) continue to be the most common disorders treated in gastroenterological practice. They are associated with higher levels of psychological distress, impaired quality of life and increased healthcare use. Despite their high prevalence, FGIDs continue to be poorly defined thus contributing to insufficient treatment options.

The main objective of the current thesis was to evaluate the level of discrepancy between patients and physicians, also referred to as incongruence, and the effect this has on psychological distress, physician satisfaction and quality of life. More specifically, we explored the effect of incongruence in a primary care setting and compared this between two patient groups: patients with an FGID diagnosis and patients with an organic diagnosis.

In order to pursue our main objective, two studies were carried out. The first study involved a systematic review examining the potential benefits of short-term educational interventions. The second study was a cross sectional mixed-methods study that aimed to explore the differences that exist between incongruent and diagnostic groups in relation to psychological distress, physician satisfaction and quality of life. This also involved assessing the aforementioned variables whilst taking into account other variables that could potentially be moderating the relationship. The final part of the study involved implemented a qualitative approach which consisted of focus groups with patients and semi-structured interviews with physicians.

The results from the first study indicated that short educational programmes could benefit both patients and physicians, yet there still appears to be limited research regarding effective programmes that specifically target symptom severity and quality of life of patients. Furthermore, training and intervention opportunities for physicians are still relatively sparse leading to difficulties when assisting patients in practice.

The findings from the analyses conducted with incongruence as a dichotomised variable showed that both incongruence and diagnosis contribute to psychological distress. Patients in the incongruent group had higher scores on psychological distress than congruent patients. On the other hand, no significant differences were found between incongruent and congruent patients in relation to physician satisfaction levels. Patients with an FGID diagnosis had higher scores on psychological distress and lower physician satisfaction levels than patients with an organic diagnosis.

The results from the analyses carried out with incongruence as a continuous variable supported this further. Statistically significant positive correlations were found for incongruence with psychological distress and age. Female patients and patients with an FGID diagnosis had higher levels of psychological distress and worse quality of life, as well as lower physician satisfaction in the case of patients with an FGID diagnosis. A statistically significant positive correlation was found only for physician satisfaction and age. When carrying out multiple regression models, we found that gender and incongruence had the greatest influence on psychological distress. Finally, from the moderation models we found that only age was a significant moderator between incongruence and psychological distress.

From the qualitative part of the research, five major themes were found when conducting a thematic analysis: (1) Illness, Emotional and Personal Problems (2) Disease-Healthcare System Interaction (3) Health system (4) Intervention and (5) Patients. From the patient focus groups key factors were outlined as needing to be addressed such as the overload of the healthcare system and long waiting lists. From the physician interviews we identified that a lack of resources and a clear referral pathway to mental health services may be contributing to the difficulties when treating these patients.

To our knowledge, this is the first study to investigate the influence of incongruence in primary healthcare settings using this procedure. Additionally, as far as we are aware this is

also the first study to explore the underlying reasons for incongruence using a qualitative approach. The findings from the thesis have allowed us to identify that incongruence could be influential in lower wellbeing and quality of life.

Keywords: gastrointestinal disorders, incongruence, psychological distress, diagnosis, physician satisfaction, primary care.

Resumen

Los trastornos gastrointestinales funcionales (TGF) siguen siendo los trastornos más habituales tratados en la práctica gastroenterológica. Están asociados con los niveles más altos de distrés psicológico, deterioro de la calidad de vida y un mayor uso de la atención médica. A pesar de su alta prevalencia, los TGF siguen estando mal definidos, lo que contribuye a opciones de tratamiento insuficientes.

El objetivo principal de la tesis fue evaluar el nivel de discrepancia entre pacientes y médicos, conocida como incongruencia, y el efecto que esto tiene sobre el distrés psicológico, la satisfacción con el médico y la calidad de vida. Más específicamente, exploramos el efecto de la incongruencia en un entorno de atención primaria y lo comparamos entre dos grupos de pacientes; pacientes con diagnóstico de TGF y pacientes con diagnóstico orgánico.

Se llevaron a cabo dos estudios. El primero involucró una revisión sistemática que examina los beneficios potenciales de las intervenciones educativas a corto plazo. El segundo fue un estudio transversal de métodos mixtos con el objetivo de explorar las diferencias existentes entre los grupos incongruentes y de diagnóstico en relación con el distrés psicológico y los niveles de satisfacción con el médico. Esto también implicó evaluar las variables previamente mencionadas teniendo en cuenta que otras podrían afectar la relación entre ellas. La última parte del estudio implementó un enfoque cualitativo que involucró grupos focales de pacientes y entrevistas semiestructuradas con médicos.

Los resultados del primer estudio indicaron que los programas educativos breves podrían beneficiar tanto a los pacientes como a los médicos, sin embargo, todavía parece haber bibliografía limitada con respecto a programas efectivos que se enfoquen específicamente en la gravedad de los síntomas y la calidad de vida de los pacientes. Además, las oportunidades de formación e intervención para médicos todavía son relativamente escasas, generando dificultades para ayudar a los pacientes en la práctica.

Los hallazgos de los análisis realizados con la incongruencia como variable dicotómica mostraron que tanto la incongruencia como el diagnóstico contribuyen el distrés psicológico. Los pacientes del grupo incongruente tuvieron mayores puntuaciones en el distrés psicológico que los pacientes congruentes. En cambio, no se encontraron diferencias significativas entre pacientes incongruentes y congruentes en relación con los niveles de satisfacción con el médico. Los pacientes con un diagnóstico de TGF tuvieron puntuaciones más altas en el distrés psicológico y niveles más bajos de satisfacción que los pacientes con diagnósticos orgánicos.

Los resultados de los análisis llevados a cabo con la incongruencia como variable continua respaldaron esto aún más. Se encontraron correlaciones positivas estadísticamente significativas para la incongruencia con el distrés psicológico y la edad. Las pacientes del sexo femenino y los pacientes con diagnóstico de TGF presentaron mayores niveles del distrés psicológico y peor calidad de vida, además de menor satisfacción con el médico que en el caso de los pacientes con diagnóstico TGF. Se encontró una correlación positiva estadísticamente significativa solo para la satisfacción con el médico y la edad. Al realizar modelos de regresión múltiple, encontramos que el género y la incongruencia tienen la mayor influencia en el distrés psicológico. Finalmente, a partir de los modelos de moderación encontramos que solo la edad fue un moderador significativo entre la incongruencia y el distrés psicológico.

De la parte cualitativa de la investigación, se encontraron cinco grandes tópicos al realizar un análisis temático; (1) Enfermedad, problemas emocionales y personales (2) Interacción enfermedad-sistema sanitario (3) Sistema sanitario (4) Intervención y (5) Pacientes. De los grupos de enfoque de pacientes, se describieron los factores clave que deben abordarse, como la sobrecarga del sistema de atención médica y las largas listas de espera. A partir de las entrevistas con los médicos, identificamos que la falta de recursos y una vía clara de derivación a los servicios de salud mental pueden estar contribuyendo a las dificultades en el tratamiento de estos pacientes.

Hasta donde sabemos, este es el primer estudio que investiga la influencia de la incongruencia en los entornos de atención primaria de la salud utilizando este procedimiento. Además, este es también el primer estudio que explora las razones subyacentes de la incongruencia utilizando un enfoque cualitativo. Los hallazgos de la tesis nos han permitido identificar que la incongruencia podría generar un menor bienestar y calidad de vida.

Palabras clave: trastornos gastrointestinales, incongruencia, distrés psicológico, diagnóstico, satisfacción con el médico, atención primaria.

1. Introduction

1.1. Gastrointestinal disorders

1.1.1. Definition and burden of gastrointestinal disorders.

Disruptions to the gastrointestinal tract result in disorders such as coeliac disease (CD), irritable bowel syndrome (IBS) and inflammatory bowel disease (IBD; Satherley et al., 2015). These gastrointestinal disorders can lead to a variety of symptoms ranging from minor symptoms to more chronic debilitating symptoms such as abdominal pain, weight loss, fatigue, tiredness, and changes in bowel habits (Bernstein et al., 2010; GESA, 2017; Morrison et al., 2009).

The global burden of gastrointestinal disease is increasing and has been estimated at 6–60 billion cases annually (Peery et al., 2012). The burden of these diseases is co-determined by symptom and disease severity, as well as the ability for patients to cope with their symptoms without significant interruption to their daily life.

Based on the recommendations proposed by the Rome IV criteria (Drossman, 2016) two of the main gastrointestinal diseases are as follows (a) Organic disorders and (b) Functional Gastrointestinal Disorders (FGIDs). The characteristics of each of the disorders has been outlined below.

1. **Organic disorders:** An organic disorder (e.g., inflammatory bowel disease) refers to structural disorders which are defined in terms of organ morphology. The disease is often classified as a pathology at a macro or micro level (Drossman, 2016). Additionally, a disorder can be classified as “organic” when an anatomical or biochemical (metabolic, enzymatic or hormonal) cause exists (León-Barúa, 1980).
2. **Functional Gastrointestinal disorders:** A functional gastrointestinal disorder can be characterised by morphologic and physiological

abnormalities which are related to any combination of factors such as motility disturbance, visceral hypersensitivity, altered mucosal, immune function, gut microbiota and central nervous system processing (Drossman, 2016; Mukhtar et al., 2019). The disorder is often classified primarily through the patient's symptoms, referred to as a noticeable change in the body that is reported by the patient as being different from normal (Drossman, 2016).

Table 1 shows clear clinical differences between the two disorders, with greater difficulties found when managing and effectively treating patients with FGIDs.

Table 1

Clinical Differences between Organic and Functional Gastrointestinal Diseases

Clinical features	Organic disease-cause evident; secondary to defined aetiology	Functional disease-cause not evident; probable primary aetiology
Age	Older (>45 years)	Younger (<45 years)
Sex	Equal incidence in men and women	More common in women than in men (in white populations)
Timing of onset	Defined onset	Poorly defined onset

Symptoms	Specific symptoms; pain rarely prominent	Multiple, diffuse symptoms; pain often prominent
Comorbidities	No other issues	Other functional syndromes are common
Psychiatric comorbidities or psychological stress	Equivalent to or slightly elevated compared with the general population	Much more common than in the general population
Intolerances	No history of intolerance to medications or diet	Self-reported intolerance to medications and diet
Therapeutic response	Response to specific therapy	Poor response to therapy
Diagnosis and outcome	Doctor and patient usually satisfied with diagnosis and outcome	Doctor and patients often unsatisfied or frustrated with diagnosis and outcome owing to nonspecific symptoms and lack of specific and effective treatments

Note. Patients with ‘organic disease’ are those with a diagnosis based on a unique pathology on histology or clinical measurement (for example, neoplasia, inflammation, major motility disorders or severe gastroesophageal reflux disease), and patients with functional gastrointestinal diseases are those with a diagnosis based on characteristic symptoms supported by the absence of a definitive pathology on investigations (for example, dyspepsia or IBS). This is adapted from the table presented by Fox et al (Fox et al., 2018).

1.2. Functional gastrointestinal disorders

The definition of FGIDs has varied greatly due to societal perspectives of the illness over time, the clinician’s training, and personal biases. FGIDs are normally defined as a group of disorders that are characterised by chronic gastrointestinal symptoms such as abdominal pain, dysphagia, dyspepsia, diarrhoea, constipation and bloating (Fikree & Byrne, 2021).

Traditionally FGIDs were considered to be conditions with no organic basis, however this definition has since evolved. Research has found that genes (Morris-Yates, 1998), subtle intestinal inflammation or immune activation (Sinagra et al., 2016; Walker et al., 2014; WALKER et al., 2009), and brain-gut axis dysfunction (Koloski et al., 2012) may be involved in a subset of these disorders (Talley, 2020).

The Rome IV criteria divides FGIDs into 33 adult disorders and six main categories, which belong to the following anatomical regions: oesophagus, gastroduodenal tract, bowel, biliary tract and anorectal area (Drossman & Hasler, 2016; Fikree & Byrne, 2021; Schmulson & Drossman, 2017). One of the most common subtypes is irritable bowel syndrome often causing abdominal discomfort, altered bowel habits and bloating. As well as functional dyspepsia which can cause epigastric pain or discomfort, and can be associated with fullness and satiety (Drossman, 2016).

1.2.1. Functional somatic syndromes, medically unexplained symptoms and comorbidities.

Functional somatic syndromes (FSS), commonly known as medically unexplained symptoms (MUS), are defined as physical symptoms that cannot be explained by an underlying organic pathology (Joustra et al., 2015). The most well-known FSS are IBS, functional dyspepsia (FD), fibromyalgia and chronic fatigue syndrome (Crabtree & Ganty, 2016; Henningsen et al., 2007, 2018; Joustra et al., 2015).

In relation to comorbidities, MUS are often accompanied with psychological distress, higher rates of anxiety, depression, social isolation and reduced quality of life (QOL) than diseases that are attributed to an organic pathology (Dirkzwager & Verhaak, 2007; Joustra et al., 2015; Zonneveld et al., 2013).

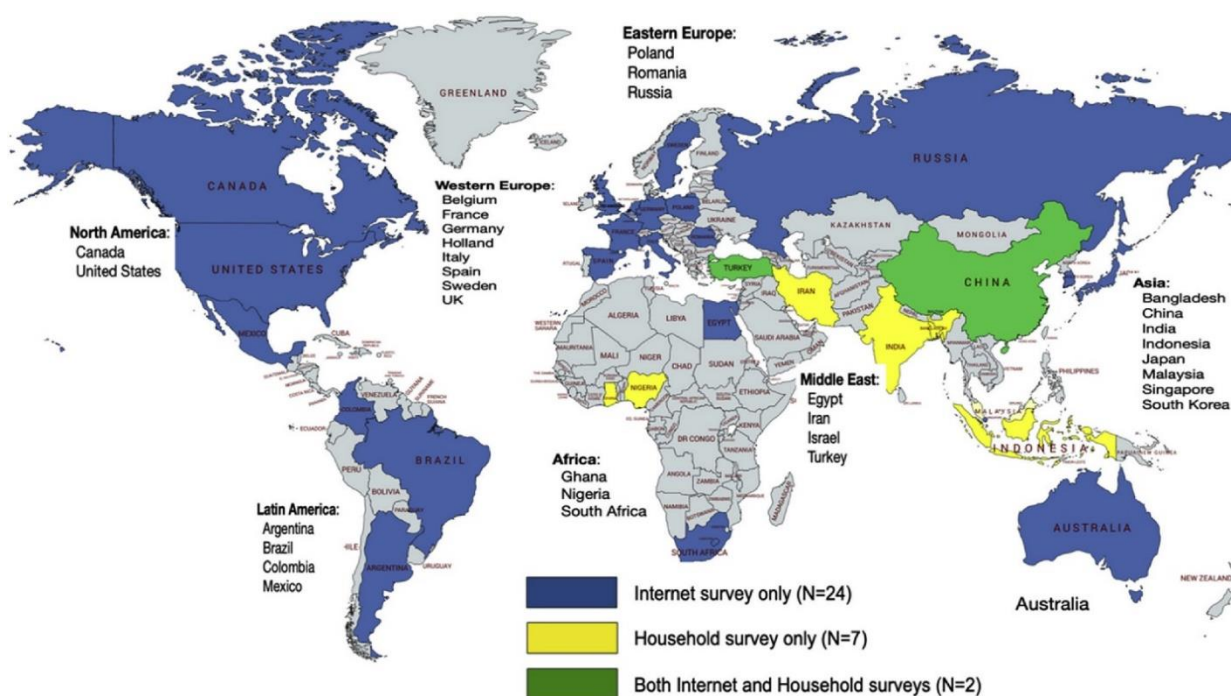
1.3. Prevalence rates of FGIDs worldwide

As previously mentioned, the Rome IV classified FGIDs into six main categories which are as follows (1) Oesophageal Disorders (2) Gastroduodenal disorders (3) Bowel disorders (4) Centrally Mediated Disorders of Gastrointestinal Pain (5) Gall Bladder and Sphincter of Oddi disorders and (6) Anorectal disorders (Drossman, 2016).

Data was collected from 33 countries using the Rome IV diagnostic questionnaire, Rome III irritable bowel syndrome questions and 80 items which were used to help identify variables associated with FGIDs (Sperber et al., 2020). Prevalence rates were gathered for five of the major FGIDs and compared across the globe. Among the 73,076 adults, a total of 36,148 women were included (49.47%) and 36,928 (50.53%) were men. As seen in figure 1, this international study used three data collection methods: the internet, household interviews or both.

Figure 1

Map of countries included colour coded by data collection method



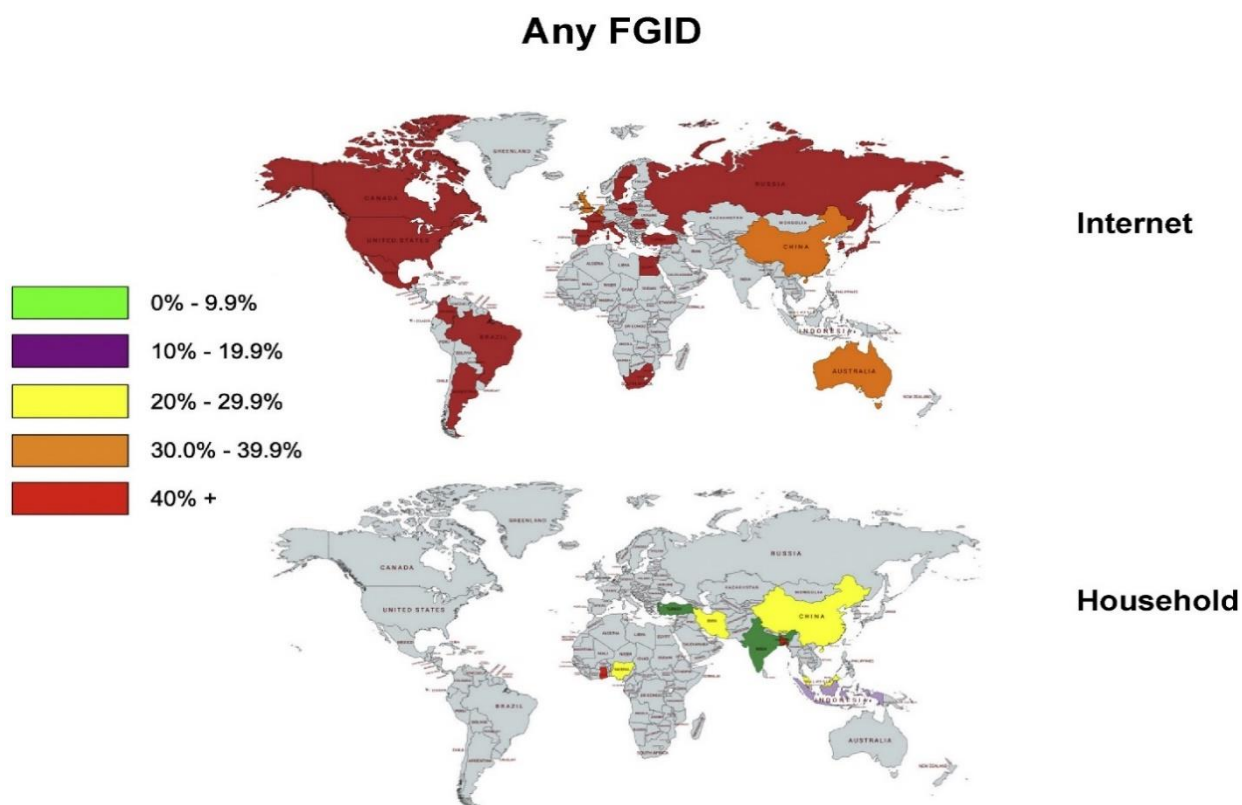
Note. This figure was originally presented by Sperber et al.(2020).

The results from this study found that more than 40% of people worldwide have an FGID. As seen in figure 2 some of the lowest rates of FGIDs (0-9.9%) came from the household

interviews conducted in Turkey and India. In contrast, higher rates (40% or more) were found in countries such as Canada, United States, Columbia, Brazil, Argentina and Russia.

Figure 2

Prevalence rates of FGIDs worldwide using internet and household surveys



Note. The figure has been adapted from the research conducted by Sperber et al. (2020).

1.3.1. Oesophageal disorders.

The most prevalent oesophageal disorder from the internet and household surveys was functional dysphagia with prevalence rates of 3.2% and 1.2% respectively. The rates for functional heartburn, reflux hypersensitivity, and oesophageal chest pain were substantially lower. Rates were higher among women for both types of collection methods, however this was not the case when concerning age. Rates decreased for older individuals in the internet countries, whereas they were found to be higher in the household countries.

1.3.2. Gastroduodenal disorders.

FD was found to be the most prevalent gastroduodenal disorder in this subcategory with rates of 7.2% from the internet survey and 4.8% from the household surveys. From the internet survey, a total of 66.6% belonged to postprandial distress syndrome (PDS), 15.3% to the epigastric pain syndrome (EPS), and 18.1% had overlapping symptoms for both PDS and EPS. In the household countries, the subtype distribution was 59.5% for PDS, 28.1% EPS, and 12.4% for overlapping PDS/EPS. The FD rates were lower in Japan (2.2%) than in Egypt (12.3%) when using the internet surveys. In comparison, the rates varied from 0.7 in India to 19.4 in Bangladesh when using the household surveys.

Similarly, to the oesophageal disorders women had higher mean rates of FD than men in the internet surveys. Additionally, FD as well as its subtypes were most common among young adults and decreased across the adult lifespan.

1.3.3. Functional Bowel Disorders.

The most prevalent disorder in this subcategory was functional constipation with rates of 11.7% and 6.6% for internet and household surveys. Other prevalent disorders were

functional diarrhoea at 4.7% and 1.2%, irritable bowel syndrome (IBS) at 4.1% and 1.5%, and functional abdominal bloating/distention at 3.5% and 1.2%.

The prevalence rates of IBS among internet survey countries ranged from 1.3% in Singapore to 7.6% in Egypt. From the 26 countries that were included, 19 of these had IBS rates between 3-5%. Apart from the countries already mentioned, the outliers were as follows: Japan (2.2%), China (2.3%), Russia (5.9%), South Africa (5.9%), and the United States (5.3%). Whereas in the household countries, IBS prevalence rates ranged from 0.2% in India to 4.6% in Bangladesh.

The prevalence rates of IBS were substantially higher among women in both survey types. IBS prevalence decreased with age in the internet surveys, from 5.3% to 3.7%, whereas it increased with age in the household group from 1.4% to 1.9%.

1.3.4. Centrally mediated abdominal pain syndrome and biliary pain.

There were almost no cases for this subcategory of FGIDs. The rate for patients with centrally mediated abdominal pain syndrome was 0.02% ($n = 9$) for the internet survey and 0.05% ($n = 9$) for the household survey. For biliary pain the rates were 0.08% ($n = 44$) for the internet survey and 0.03% ($n = 5$) for the household survey.

1.3.5. Anorectal Disorders.

From the internet survey 8.1% met criteria for at least one anorectal disorder, compared to 2.7% in the household surveys. The most prevalent disorder for both types of survey methods was proctalgia fugax, 5.9% from the internet surveys and 1.7% in the household surveys.

1.4. The Burden of FGIDs

FGIDs are prevalent conditions affecting approximately one third of the population (Koloski et al., 2002; Lovell & Ford, 2012a). Primary care is the setting where most patients with mental illness initially present, yet patients with depression and anxiety who attribute the symptoms they experience to a physical problem often go undiagnosed (Kessler et al., 2005; Petterson et al., 2014; Schulberg & Burns, 1988). Additionally, FGIDs are commonly associated with high physician consultations (Choung et al., 2017; Kaji et al., 2010; Pinto-Sanchez et al., 2015; Sperber et al., 2020; Vakil et al., 2016), as well secondary costs due to impaired workforce productivity and absenteeism (Reilly et al., 2004).

FGIDs account for a large portion of gastrointestinal consultations seen in primary and secondary care, and approximately 30% of these patients go on to develop chronic symptoms (Boyce et al., 2006; Chang, 2004; Drossman et al., 1993; Ford et al., 2010, 2015; Halder et al., 2010; Locke, 1996; Locke et al., 2005; Lovell & Ford, 2012a, 2012b; Park et al., 2011; Qumseya et al., 2014; Soares & Ford, 2011; Talley, 2008; Talley & Boyce, 2002; W. Wu et al., 2013).

Due to the increase in prevalence rates and difficulties in diagnosing patients, FGIDs have become an emerging problem in gastroenterology (Suciu et al., 2019). They represent a public health burden given their chronic remitting-relapsing course which significantly impacts the patient's general wellbeing (Chang, 2004; Talley, 2008). As measured on the Patient-Reported Outcomes Measurement Information System (PROMIS) global-10 questionnaire, Health-Related Quality of Life (HRQOL) for individuals diagnosed with an FGID is much lower compared to individuals with no FGID diagnosis (Sperber et al., 2020).

The diagnosis and management of FGIDs can be challenging for healthcare providers (HCPs). Clinicians that may not have been given sufficient training in the diagnosis and treatment of these patients may feel that they are unable to effectively manage them, or they

may see these patients as being out of their realm of responsibility. This can lead to poor communication, negative attitudes, ordering of procedures that are unlikely to provide meaningful information or placing a greater focus on “organic” or “sicker” patients (Drossman & Ruddy, 2020). Furthermore, the response to treatment, as well as treatment failure is common which results in an increased use of healthcare resources (Mira et al., 2018). Previous studies in Spain and the UK have showed that patients are sceptical about the treatments they receive, they feel that they have insufficient knowledge of IBS and do not benefit from the treatments they are given (Harris & Roberts, 2008; Mira et al., 2015). In a recent study conducted on patients with chronic musculoskeletal pain there were substantial differences in the patients and physicians’ priorities for treatment. This may be as a result of physicians focusing on functional goals and medication side effects such as reducing opioid use, in contrast patients were more likely to focus on symptom relief, i.e., reducing pain intensity (Henry et al., 2017). Likewise contrasting views between clinicians and patients level of functionality also appear to be related to higher levels of psychological distress for patients with FGIDs in tertiary care settings (Eiroa-Orosa et al., 2016; Rodriguez-Urrutia et al., 2016, 2017). These differences can lead to depression in medical conditions and patient dissatisfaction (Drossman & Ruddy, 2020; Halpert et al., 2018; Lieberman et al., 1996).

Despite their high prevalence there is limited data regarding the impact this disorder has on health in the general population and in secondary care settings (Aziz et al., 2018). Whilst an assessment of psychosocial factors may be influential in identifying individual vulnerability to illness, primary care physicians (PCPs) or medical specialists often omit this information (Fava et al., 2010).

1.5. The Biopsychosocial model as a holistic approach to FGIDs

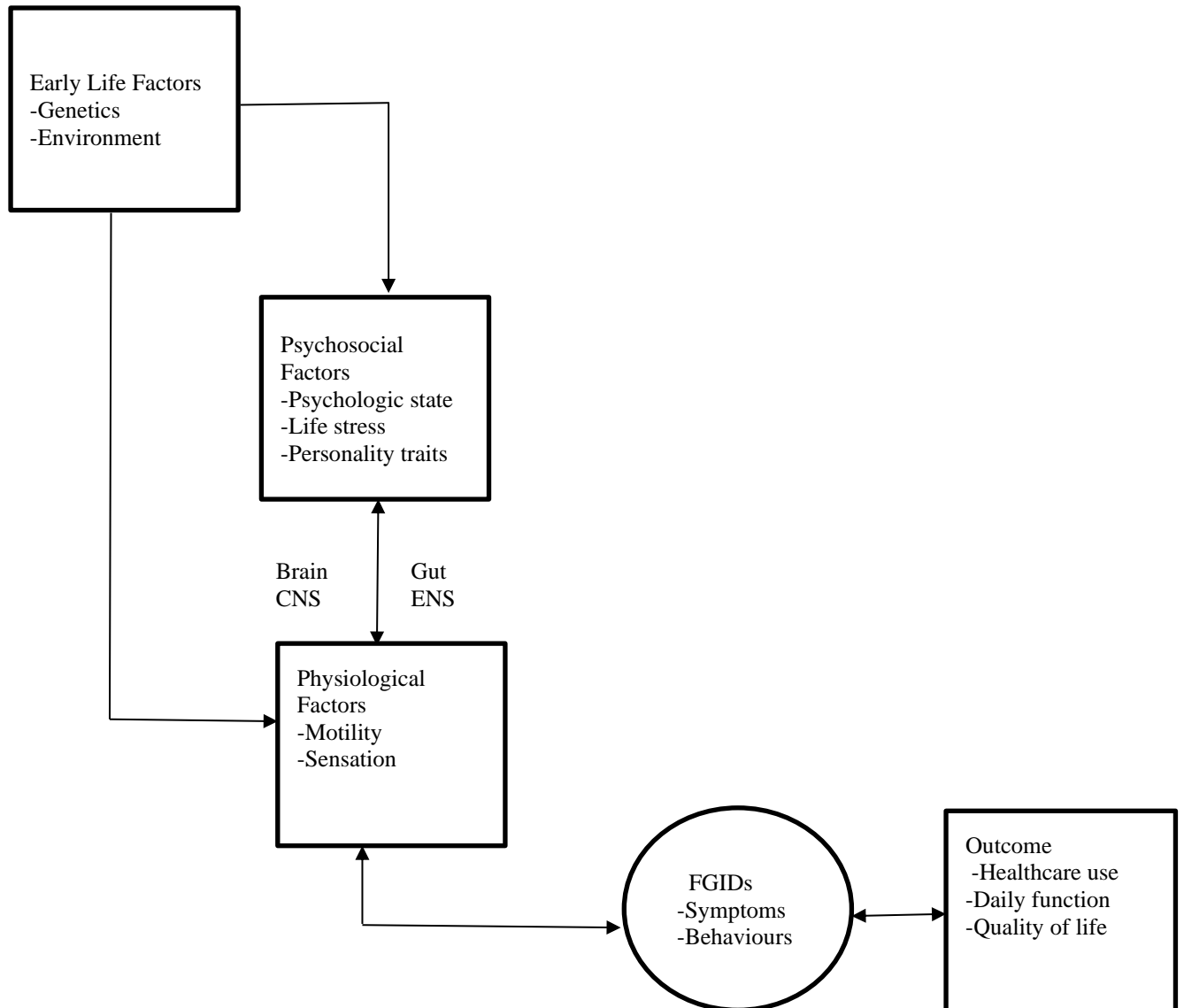
In 1977 Engel challenged the medical profession to reconsider the biomedical approach to medical education and instead encouraged a new medical model known as the biopsychosocial model (Engel, 1977). Engel proposed that humans are biological, psychological, and social beings who behave in certain ways which can promote or harm their health. Many interacting factors from the cellular to the social contribute to health and illness. Engel proposed that if physicians are to understand and potentially heal a patient's illness, instead of providing a diagnosis and a cure, they must understand the nature of these interactions.

The research conducted by Engel caused many investigators and clinicians to change the way that they viewed FGIDs. Instead of seeking specific underlying biological aetiologies they began to use a more integrated approach to understand illness and disease. The biopsychosocial model outlines the effect that early life, psychological stress, and psychosocial factors can have on the development of the illness. For instance, a person's genetic composition may lead to a greater susceptibility of developing the illness which may be exacerbated depending on the individual's response to stress, as well as exposure to psychosocial factors. Thus, FGIDs are a product of interactions between psychosocial factors and altered gut physiology via the brain-gut axis (Mayer et al., 2014).

The biopsychosocial model is depicted in figure 3, this illustrates the interaction between biological, psychological and social factors (Drossman, 2016; Mukhtar et al., 2019).

Figure 3

The biopsychosocial model pathogenesis, clinical experience, and effects of functional GI disorders



Note. This figure is based on the work presented by Drossman (2016).

1.5.1. Early life factors.

1.5.1.1. The influence of genetics and parental behaviours.

A person's genetic composition and interactions with the environment can affect the susceptibility of developing the disease, and the phenotypic expression. Multiple genes are likely to interact with environmental factors to produce FGID symptoms. Other factors such as psychophysiological components, sociocultural aspects and family interactions are likely to lead to the expression of FGIDs (Drossman, 2016).

Although there is ongoing research into a genetic explanation for familial patterns, it has been found that the behaviours that children learn from parents are more influential in the development of FGIDs than genetics (Levy et al., 2001). Parents represent one of the most important contextual factors as children often learn adaptive or maladaptive illness-related behaviours from their parent (Levy, 2000). For instance, research showed that children whose mothers reinforce illness behaviour experienced more severe stomach aches and more school absences than other children (Levy et al., 2004).

1.5.1.2. The link between trauma and FGID symptoms.

Patients with FGIDs are likely to report trauma more often than healthy individuals or patients with an organic disorder (Suciu et al., 2019). Compared with controls, IBS patients report a higher prevalence of adverse life events in general such as physical punishment, emotional abuse, and sexual abuse (Bradford et al., 2012). Prospective studies have demonstrated that the experience of stressful life events is associated with symptom exacerbation and frequent health seeking among adults with IBS (Lackner & Gurtman, 2004; Sperber et al., 2012). Healthcare seeking behaviour by IBS patients is largely driven by psychological distress (Drossman et al., 1988; Ringström et al., 2007). Recent findings have

indicated that over users of patient-initiated consultations have higher scores on dependency, compulsivity, anxiety and major depression (Gomà-i-Freixanet et al., 2019).

Traumatic events may also lead to symptom expression due to an increase in maladaptive coping and the triggering of psychiatric conditions which may cause higher levels of pain sensitivity (Suciu et al., 2019). Individuals exposed to trauma tend to display heightened autonomic and hypothalamic-pituitary-adrenal responses to physical and psychological stressors. The psychological trauma may also lead to other changes in the body such as altering of visceral sensitization (Suciu et al., 2019).

1.5.2. Psychosocial factors.

1.5.2.1. The Presence of anxiety and depression.

Psychological factors such as anxiety and depression have long been known to be associated with FGIDs (Koloski et al., 2020). There is growing evidence that FGIDs and psychological disorders exist in the community and in primary care settings suggesting that there is a relationship between psychological comorbidity and FGIDs (Patel et al., 2015; Rosendal et al., 2017).

Anxiety has been found to be high among this subgroup of patients; in fact, anxiety disorders are the most common psychiatric comorbidity as they are prevalent in approximately 30-50% of FGID patients (Van Oudenhove et al., 2016). In addition, the overlap between depression and FGIDs is about 30% in primary care settings, this has been reported as being even higher in tertiary care (Addolorato et al., 2008). Comorbid depression has been linked to poorer outcomes such as high healthcare utilization and worse treatment engagement (Lackner et al., 2010; Lackner & Gurtman, 2005). Thus, psychological distress is an important risk factor for the development of FGIDs, which can exacerbate or perpetuate symptoms. This can

negatively affect the doctor-patient relationship and treatment outcomes (Van Oudenhove et al., 2016).

1.5.3. Personality traits.

In a recent review the effect of personality traits, using the five-factor model (i.e., neuroticism, extraversion, openness to experience, agreeableness, and conscientiousness), personality constructs (i.e., alexithymia and distressed- Type D personality) and emotional patterns (i.e., negative and positive) were assessed in order to examine whether the aforementioned factors were influential in the clinical expression, pathophysiology and outcome of IBS. Several personality traits and constructs, for instance neuroticism, conscientiousness and alexithymia were closely related to IBS. Additionally, certain emotional patterns such as negative emotions seemed to play a key role in the dysfunction of the brain-gut axis (Muscatello et al., 2016).

Additionally, there are specific maladaptive cognitive affective processes known to impact GI symptom experience at the level of the brain (Naliboff & Mayer, 2006). For instance, these include catastrophizing, cognitive inflexibility, fear of symptoms, hypervigilance and attentional bias to benign gut sensations (Keefer et al., 2018).

1.5.4. The ‘brain-gut axis’ or the ‘gut-brain axis’.

The Rome IV recognises that the gut-brain interaction axis is a basis for functional gastrointestinal disorders. The biopsychosocial aspects on previous exposures, experience and stressors can influence the susceptibility to gastrointestinal (GI) dysfunction with reciprocal influences between the gut and the brain. The neural wiring between the gut and the brain communicates information between various parts of the GI tract and emotional and cognitive centres of the brain. These systems operate via neurotransmitters to regulate GI functions and

pain sensations with secondary influences of mental functioning entangling anxiety disorders and depression (Hellström & Benno, 2019).

FGIDs are normally considered as having no pathology and to be due to an unknown cause, however various alterations have been found in the brain-gut axis such as visceral hypersensitivity (Holtmann et al., 2016; Lacy et al., 2016; Simrén et al., 2019; Stanghellini et al., 2016). Traditionally, both IBS and FD have been conceptualized as brain-gut disorders (Talley, 2020). It is implied that mood disorders “cause” gastrointestinal symptoms, however epidemiological data now provides strong evidence that in some cases gastrointestinal symptoms arise first and mood disorders occur later, while in other patients the reverse appears to happen (Drossman & Hasler, 2016; Holtmann et al., 2017).

Koloski et al. (2012) investigated this concept by conducting a prospective 12-year follow up population-based study with more than 1,000 individuals. The results showed that among asymptomatic subjects that higher levels of anxiety but not depression at baseline was a significant independent predictor of developing an FGID over a 12-year period (Koloski et al., 2012). The evidence suggests psychological distress is not simply a comorbidity but an essential part of the expression of FGIDs, and for many it may directly occur because of alterations in the intestinal tract. While patients with FGID are susceptible to developing significant gastrointestinal symptoms in response to a variety of external stimuli, it is equally possible that for some FGID patients it is more likely to manifest with psychological distress or mental health conditions if they are exposed to psychological stressors. Whether psychological factors are causal or supplementary in FGIDs has remained controversial but new evidence is emerging which will help to provide greater clarification (Koloski et al., 2020). Based on the Bradford Hill criteria for causation, psychological factors likely play a causal role for a subset of individuals with FGIDs. This view is based on strong data from prospective population-based studies, which have found on average that they are twice as likely to develop

IBS at a later time if anxiety or depression were present at baseline. While some patients are now considered to have a brain-gut disorder, there is also a significant proportion of individuals with FGIDs where psychological factors likely arise secondary to the intestinal disease and thus are considered to have a gut-brain disorder (Koloski et al., 2020).

1.5.5. Physiological factors.

A variety of physiological factors may be responsible for GI disorders and functional GI disorders. As stated by Drossman (2016) these occur due to a number of reasons, some of which have been listed below.

1.5.5.1. The effect of abnormal motility, visceral hypersensitivity, and the microbiome.

Symptoms such as nausea, vomiting and abdominal pain can occur as a result of changes in gastrointestinal motility. For patients with FGIDs, factors such as environmental stress via the brain-gut axis can lead to dysmotility through the GI tract.

Another possible reason for the development or continuation of FGID symptoms is due to visceral hypersensitivity. This refers to the altered sensation which is in response to a physiological stimuli. Visceral hypersensitivity is a biopsychosocial disorder and may be amplified in patients with IBS or FD. This sensitivity or hypersensitivity may be increased at all levels of the brain-gut axis.

Lastly, the microbiome represents the collection of microorganisms which are shaped by genetics and nutrients and in turn can influence health and disease. It has become a vital factor in gut functioning and in FGIDs which has led to a new concept known as the 'microbiome-brain-gut axis' (Mayer et al., 2014; Pigrau et al., 2016). For instance, differences have been found in patients with IBS in relation to their bacterial composition compared to

healthy individuals, thus indicating that the microbiome may play a significant role in the onset and maintenance of certain FGIDs such as IBS.

1.5.6. Potential risk factors affecting symptom expression and QOL.

1.5.6.1. Gender and social factors.

Health and illness occur within a larger social context; thus, the expression of the illness is dependent on several social determinants. For instance, it is dependent on life stressors, history of abuse, and early life experiences such as gender role socialisation, social support and social factors all of which are assessed by QOL scales.

There is evidence to suggest that there are gender differences in the development of FGID. For example, many of the symptoms expressed by patients with FGIDs such as bloating, constipation, chronic functional abdominal pain and pelvic floor dysfunction are more prevalent in woman than in men. On the other hand, functional oesophageal and gastroduodenal disorders do not appear to be affected by gender (Chang et al., 2006).

Studies that have investigated whether women and men with FGIDs differ on health-related QOL measures have also found differences between the two genders (Tang et al., 2012). For instance, in one study women with IBS reported a lower QOL compared with men who had IBS (Simrén et al., 2001). This was also found to be the case in a Chinese outpatient population (Tang et al., 2012).

1.5.6.2. Cross-cultural differences.

A patient's culture is related closely to religious principles, language (the explicit expression of symptoms and feelings) and explanatory models of illness. The effect of culture on health and healthcare can manifest itself in illness beliefs, symptom expression and learned coping patterns. Cultural and ethnic factors may also affect pathophysiology, the patient-

physician relationship, the diagnostic process (Dimsdale, 2000), the openness to treatment modalities, and psychotherapy (Dimsdale, 2000; Ng et al., 1996).

Regardless of if the patient and physician speak the same language, misunderstandings continue to take place. This is particularly the case for FGIDs as symptoms are vague and numerous and there is no robust way of objectively quantifying them (Francisconi et al., 2016).

1.6. Closing the gap between patients and primary care physicians

1.6.1. Psychosomatic Medicine and Psychosocial Assessment.

Psychosomatic medicine is a wide interdisciplinary field that is concerned with the interaction between biological, psychological and social factors in regulating the balance between health and disease (Fava et al., 2017). More specifically this deals with the mechanisms by which emotion, cognition, behaviour or social factors may be influencing physical disease, or alternatively how this physical disease may result in altered emotion, cognition or behaviour (Lane, Waldstein, Chesney, et al., 2009; Lane, Waldstein, Critchley, et al., 2009).

Psychosomatic medicine considers the assessment of psychosocial factors that may be affecting individual susceptibility to illness, the outcome of the disease, a holistic consideration of patient care and the integration of psychological therapies as a method of preventing and treating different medical conditions (Fava & Sonino, 2009).

A large body of research has highlighted the influential role that stressful life events and repeated or chronic environmental challenges have in modulating individual vulnerability to illnesses. The tendency to experience and communicate psychological distress in the form of physical symptoms and to seek medical help for them is a widespread clinical phenomenon. Evidence has accumulated in psychosomatic research for the need of a more comprehensive assessment that includes the psychosocial variables (e.g., interpersonal relationships providing

a buffering role for stress) and the evaluation of the psychosocial correlates (e.g., QOL) of the medical disease (Fava & Sonino, 2009). Effectively assessing these factors may be crucial in managing patients with unexplained medical symptoms and can help to explain difficult doctor-patient relationships (Fava et al., 2007; Fava & Wise, 2007; Leplège, 1997; Porcelli & Sonino, 2007; Prince et al., 2007; Sonino & Peruzzi, 2009).

Psychosomatic medicine has pioneered the self-rated evaluation of psychological status in medical conditions (Fava et al., 2011) such as the 'Symptom Checklist-90' (Derogatis et al., 1973) which has been extensively used in medical settings (Bech, 2012, 2016). Research in this area seeks two kinds of information: the functional status of the individual and the patient's appraisal of his or her own health. Indeed, the subjective perception of health status (i.e., lack of well-being) is as valid as that of the clinician in evaluating outcomes (Bech, 1990; Rodriguez-Urrutia et al., 2016; Topp et al., 2015).

The collection of patient and practitioner data could also be an important way to improve quality and efficiency of health care delivery (Murdoch & Detsky, 2013). Studies examining QOL in patients with chronic illnesses have helped physicians address the difficulties that patients face between consultations. Struggles may include the onset of undiagnosed symptoms, the process of diagnosis, the experimentation with treatments and in some cases the restructuring of a patient's personal identity (McCormick et al., 2012).

In addition, obtaining information regarding the perceptions that patients have about the public health system is an important step towards closing the gap between patients and PCPs. A previous study which was conducted in Spain analysed the problems experienced with IBS management within the public healthcare system acquiring both the patient's and the HCP's perspective (Mira et al., 2015). The results indicated that patients were most concerned with delays in confirming a diagnosis, the inability to understand IBS and to cope with the disease on a day-to-day basis. The HCPs felt that the greatest challenge when treating patients

with IBS was the low adherence to treatment plans. Further understanding of the barriers to achieving a positive patient-HCP relationship need to be understood better in order to improve patient outcomes (Mira et al., 2015).

The interest in health promotion rather than disease prevention is considered an important step towards achieving more effective patient care and self-management. Focusing on the importance of the patient-physician relationship could encourage patients and physicians to make health related decisions together (Joosten et al., 2008).

1.6.2. Psychological treatment models and education to effectively manage patients with FGIDs.

Brain–gut psychotherapies, such as cognitive-behaviour therapy (CBT) refer to specific psychological techniques that focus on GI problems. These therapies have the capacity to reduce health care utilization (Van Oudenhove et al., 2016) and symptom burden (Ballou & Keefer, 2017; Ford et al., 2014), especially when they are incorporated into GI practice settings (Kinsinger et al., 2015; Regueiro et al., 2016; Riehl et al., 2015a). Brain–gut psychotherapies are normally short-term and GI symptom–focused. They typically focus on the skills needed to manage unpleasant GI sensations, decrease avoidance behaviours, build resilience to stress and promote lifestyle changes (Keefer et al., 2018).

Educating patients about the brain–gut axis early in the relationship is helpful as referring a patient with an FGID for psychological treatment is often a delicate matter (Keefer et al., 2018). Patients will generally consult a gastroenterologist with the expectation of being investigated for an organic disease. They may not be aware of the influences of emotions and the brain on gastrointestinal functioning, thus an introduction of the brain-gut relationship and psychological treatment of the disorder from the beginning may be vital in overcoming this challenge. For example, this can be in the form of a brochure given at the end of the first

consultation, as well as incorporated in education of the patient when the diagnosis is explained to them (Palsson & Whitehead, 2013).

In Spain initial treatments may initially involve patient education and instructions for achieving a specific, balanced diet and exercise (Mearin et al., 2016). Psychological interventions such as CBT and gut-directed hypnosis are effective as they can explain the brain-gut axis in the context of a dynamic and active communication pathway (Mira et al., 2018). The successful treatment of FGIDs such as IBS requires a strong relationship between the patient and the HCP (Halpert & Godena, 2011; Mira et al., 2015), where the HCP educates the patient regarding the usefulness of certain diagnostic tests and treatments (Lacy et al., 2016).

1.6.3. Gastroenterologist-only specialist clinics.

In one systematic review the effect of standard outpatient gastroenterologist-only care was evaluated for patients with FGIDs (Basnayake et al., 2020). For instance, one of the studies described a cohort of patients with IBS who were seeing a gastroenterologist for the first time. The QOL questionnaire (i.e., EuroQoL-5D) was administered before the initial consultation, at 3 months and 12 months after the initial consultation. The patients showed no significant differences in QOL after treatment (Canavan et al., 2015).

In another study, all referrals were assessed over a 12-month period to a clinic staffed only by gastroenterologists. All patients with a FGID were asked to complete a survey one year after their clinical care was completed. Symptoms, absenteeism from work, expectations of the clinical service and their medical record review were evaluated. One year after the conclusion of treatment, only a minority of patients reported symptom improvement. Additionally, 62% of patients felt their symptoms had stayed the same or had become worse (Basnayake et al., 2019).

1.6.4. Psychological services integrated into gastroenterology clinics.

Kinsinger et al (2015) described a specialist clinic that integrated psychologists into gastroenterological care by offering patients a variety of psychotherapeutic services. From 259 patients, nearly half ($n= 118$) who were referred to the psychologist attended the session, and 87 patients continued with psychological care after their first consultation. The care that patients received was predominantly gut-directed hypnotherapy (48%) and cognitive behavioural therapy (44%). Patients with a functional gut disorder who attended the psychologist had significantly fewer medical procedures after clinic attendance than those who did not see a psychologist or have hypnotherapy. There was no difference in the number of physician office consultations during and after these treatments than in those patients who did not have these treatments (Kinsinger et al., 2015).

A study conducted by Kruiemel et al (2015) described a cohort of patients with complex FGIDs who failed with standard treatments and were routinely referred to an integrated joint consultation with a psychiatrist and gastroenterologist. Out of the 137 patients that were referred, 124 attended their appointment with 72 completing questionnaires six months after the joint consultation. From the 77 patients who had access to psychological services, 70 were referred for medication, psychotherapy or both. The most common psychological therapy was individual psychotherapy with a psychiatrist. After six and 12 months, 72 patients showed significant improvements in psychological wellbeing as measured by the 'Hospital Anxiety and Depression Scale and State-Trait Anxiety Inventory'. Additionally, there was a significant improvement in the patient's QOL after six and 12 months as measured by the psychological and physical domain of the SF-36. However, there were no significant reductions in gastrointestinal symptom scores at 12 months. The authors suggest that improvements in QOL and psychological wellbeing were due to the effectively targeting the psychological comorbidity which is very common for patients with FGIDs (Kruiemel et al., 2015).

1.6.5. Educational programmes and group-based interventions.

The literature on patient education ranges from the provision of booklets and instructions to extensive individual or group-based education programmes. Group-based educational interventions have been found to be superior to both written information and individual-based alternatives (Bengtsson et al., 2006; Colwell, 1998; Håkanson et al., 2012; Heitkemper et al., 2004; Ringström et al., 2010; Robinson, 2006; Saito et al., 2004).

For instance, one educational programme which implemented the clinical care model found that after taking part that patients had a growing readiness to improve wellbeing. This was based on the premise that providing patients with the opportunity to share illness experiences with others combined with professional scientific knowledge facilitates learning experiences and can enable individuals to find useful strategies for managing their everyday illness symptoms (Håkanson et al., 2012). Research has outlined a number of benefits from patient education programmes such as an improvement in symptoms health-promoting behaviours, increased coping and an enhancement in QOL. Findings from one patient educational programme indicated that patients were more self-secure, were more prepared in managing their symptoms, and better able to maintain their well-being after taking part. This was in part due to the better understanding they had regarding their illness, as well as the opportunity to listen to the illness stories of others (Håkanson et al., 2012).

A study using the concepts proposed by the Self-Efficacy Theory and the Biopsychosocial model found that patients made positive improvements after taking part in an 'IBS school'. These patients learnt about mechanisms related to enhancing skills mastery, reinterpretation of physiological symptoms, and modelling (Bandura, 1977; Lorig, 1996) Patients were encouraged to try new treatments and adapt their lifestyle, as well as assess the effect this had on their symptom severity. Patients were also provided with the opportunity to share their own experiences with other patients regarding methods and strategies that they had

found to be useful when managing their symptoms. The results showed that compared with the guidebook group the education group displayed greater reductions in IBS symptom severity and gastrointestinal specific anxiety. Additionally, several aspects of HRQOL were significantly improved after the group education which did not appear to be the case for the group who only received the written information (Ringström et al., 2010).

1.7. Training opportunities and educational programmes for physicians

Physicians have adopted a variety of approaches to managing patients with FGIDs and MUS, for instance by exploring psychological, social and physical factors separately or by attempting to integrate them (Warner et al., 2017). The literature on how medical students are trained to manage patients is very limited (Joyce et al., 2017).

There is a consensus among physicians that repeated referrals and investigations are not helpful, are likely to be costly and may lead to worse outcomes. Inconsistencies between different clinicians risked portraying contradictory messages to the patient and losing the patient's confidence and trust. A recent study which explored medical students' attitudes towards patients with MUS found that negative attitudes may be due to a lack of formal training, and that senior role models were found to be influential in shaping students' attitudes and approaches (Shattock et al., 2013). One survey given to different UK medical schools found that functional syndromes were entirely absent in some medical curricula, and if they were present, this typically accounted for less than a day of teaching (Howman et al., 2012). Additionally, one study found that a brief training given to medical undergraduates in IBS and chronic fatigue syndromes led to improvements in student knowledge and attitudes towards these patients (F. Friedberg et al., 2008).

2. Objectives and Hypotheses

In order to achieve the main objective of the thesis, smaller objectives and hypotheses have been formed and divided across two studies. Based on recommendations from the literature, research questions were produced for studies involving a qualitative component: studies 1 and stage two of study 2 (Levitt et al., 2018). In contrast, for study 2 stage one specific hypotheses were developed and have been listed below.

Study 1, which has since been published (see Appendix A), aimed to identify whether a gap exists regarding educational interventions or training opportunities available for digestive patients and physicians, the potential benefits of this on patient outcomes and the physician approach towards this subgroup of patients, as well as the techniques found to be most beneficial for the former and the latter. The first stage of study 2 aimed to provide information regarding the level of inconsistency between the clinician's and patient's perceptions in other healthcare settings. Furthermore, the aim of this part of the study was to assess the impact of incongruence and the relationship that it has with psychological distress for patients with digestive disorders. The second stage of study 2 aimed to contextualise the knowledge obtained in the primary care settings and to explore the attitudes that patients have regarding the healthcare system and health services. In addition, it aimed to obtain a perception from medical professionals to understand the patient's psychological distress in the context of a disease.

2.1. Objectives

2.1.1. Main objective.

The main objective of the current thesis was to firstly assess whether short-term educational interventions for patients with FGIDs or medically unexplained symptoms can lead to positive changes in quality of life and symptom severity (study 1). Additionally, whether

training opportunities and educational interventions for physicians working with this subgroup of patients can positively affect physician beliefs and attitudes (study 1).

Furthermore, the main objective was to improve our understanding regarding discrepant views between patients and physicians (incongruence) in a primary care setting. As well as to establish if differences exist between patient groups (functional diagnosis v organic diagnosis) and to explore the relationship between these variables with psychological distress, physician satisfaction and QOL (study 2, part one). Lastly, the thesis aimed to explore some of these discrepancies from the point of view of the patient and the medical professionals treating this subgroup of patients (study 2, part two).

2.1.2. Specific Objectives for Study 1.

O1.1. The objective of the review was to explore the scientific literature regarding short-term educational interventions for patients with FGIDs or medically unexplained symptoms, focusing specifically on the effect this has on quality of life and symptom severity.

O1.2. The objective of the review was to evaluate the current training opportunities and interventions available for physicians working with patients with FGIDs or medically unexplained symptoms and the effect this has on physician beliefs and attitudes.

2.1.3. Specific Objectives for Study 2.

2.1.3.1. *Objectives for the analyses with incongruence as a dichotomous variable.*

O2.1. To compare the sociodemographic variables: age, gender, educational level, marital and employment status with the independent variable incongruence.

O2.2. To determine the patient's clinical functioning and their satisfaction regarding the relationship they have with the physician.

O2.3. To identify if a link exists between psychological distress, incongruence and diagnosis.

2.1.3.2. *Objectives for the analyses with incongruence as a continuous variable.*

O3.1. To compare the sociodemographic variables age, gender, relationship status, educational level and employment status between completers and non-completers. Patients were categorised as completers if they had completed both the ‘Brief Symptom Inventory’ evaluation and the ‘Patient-Doctor Relationship Questionnaire’.

O3.2. To examine differences for between groups for gender on incongruence, psychological distress, physician satisfaction and QOL. To identify the relationship of age with the aforementioned variables.

O3.3. To investigate whether incongruence, age, gender, physician satisfaction and diagnosis could significantly predict psychological distress.

O3.4. To examine the moderating role of physician satisfaction, age, gender and diagnosis on the relationship between incongruence and psychological distress.

2.1.3.3. *Objectives for the qualitative part of the research exploring the perspectives of incongruent patients and primary care physicians.*

O4.1. The objective was to gain the views from incongruent patients regarding the healthcare system.

O4.2. We aimed to establish to what extent having a gastrointestinal disorder affects the daily functioning and QOL of incongruent patients.

O4.3. The objective was to establish physician views and understand to what extent resources are available to patients with FGIDs. To establish key differences in the management of patients with FGIDs compared to patients with other gastrointestinal disorders, as well as to

understand how this may be contributing to incongruent appraisals between patients and physicians.

2.2. Main hypothesis

The main hypothesis of the thesis was that the lack of understanding between physicians and patients regarding the psychological distress associated with the physical pain is a key reason for the difficulties that physicians have when managing patients with a gastrointestinal diagnosis. Based on previous findings which used this approach in a tertiary care setting (Eiroa-Orosa et al., 2016; Rodriguez-Urrutia et al., 2016, 2017), we hypothesised that incongruence, which is based on the differing view that patients and physicians have regarding the patient's quality of life, will also be present in primary care outpatient units. We expected that patients with incongruent views with physicians would have greater psychological distress (i.e., higher scores on somatisation, depression, and anxiety) than congruent patients. On the other hand, we anticipated that patients with incongruent views with physicians would have lower physician satisfaction than patients with congruent views with physicians. We also predicted that due to the nature of functional gastrointestinal disorders that this subgroup of patients would have higher levels of psychological distress, worse quality of life and lower patient satisfaction levels than patients with an organic diagnosis.

2.2.1. Research questions for Study 1.

R1.1. For patients with FGIDs or medically unexplained symptoms, to what extent can a short educational intervention improve quality of life and symptom severity?

R1.2. For physicians working with patients with FGIDs or medically unexplained symptoms, to what extent can a short-educational intervention or training opportunities lead to more positive beliefs and attitudes that they have towards this subgroup of patients?

2.2.2. Hypotheses for Study 2

2.2.2.1. *Specific hypotheses for the analyses with incongruence as a dichotomous variable.*

H1.1. We expected to find differences for the variable incongruence. In other words, we anticipated that there would be statistically significant differences between patients with incongruent and congruent appraisals for all of the sociodemographic variables. We predicted that patients with incongruent appraisals with physicians would most likely be older, female, have lower levels of education, less likely to be married or in a stable relationship and be in employment than patients with congruent appraisals with physicians.

H1.2. We predicted higher [overall] psychological distress scores, as well as for each of the different subscales (e.g., somatisation, depression and anxiety) for patients with incongruent appraisals with physicians compared to those with congruent appraisals.

H1.3. We predicted higher [overall] psychological distress scores, as well as for each of the different subscales (e.g., somatisation, depression and anxiety) for patients with a functional gastrointestinal diagnosis compared to patients with an organic diagnosis.

H1.4. We anticipated higher physician satisfaction scores for patients with congruent appraisals with physicians compared to those with incongruent appraisals with physicians.

We also predicted higher physician satisfaction scores for patients with an organic diagnosis compared to patients with a functional gastrointestinal diagnosis.

H1.5. We expected statistically significant differences in psychological distress scores based on the type of appraisal (incongruent v congruent) that the patient had with their physician (*this hypothesis attends to the first main effect*).

We expected statistically significant differences in psychological distress scores based on the diagnosis (functional v organic) of the patient (*this hypothesis attends to the second main effect*).

We expected to find statistically significant differences in psychological distress scores based on the type of appraisal that the patient had with their physician and the patient's diagnosis (*this hypothesis relates to the interaction effect*).

2.2.2.2. *Specific hypotheses for the analyses with incongruence as a continuous variable.*

H2.1. From the sociodemographic variables we expected to find a statistically significant difference between the mean age of patients who completed the study compared to those who did not complete the study. We also expected to find differences between the two groups regarding other sociodemographic variables.

H2.2. We expected that incongruence scores would be positively correlated with psychological distress. We also anticipated that incongruence would be negatively correlated with the mental health component score.

H2.3. We expected higher incongruence scores for patients with a functional gastrointestinal diagnosis than patients with an organic diagnosis.

We also predicted lower QOL for patients with a functional gastrointestinal diagnosis than patients with an organic diagnosis.

H2.4. We anticipated that incongruence would be negatively correlated with physician satisfaction.

H2.5. We expected that female patients would have higher incongruence scores, [overall] psychological distress, as well as for each of the different psychological distress subscales than male patients. We expected that female patients would have lower quality of

life than male patients. We also explored whether female patients would have lower physician satisfaction than male patients.

We expected that age would be positively correlated with incongruence, [overall] psychological distress, its subscales and physician satisfaction. We predicted that age would be negatively correlated with QOL.

H2.6. We predicted that the variables incongruence, age, gender, physician satisfaction and diagnosis would significantly predict [overall] psychological distress.

H2.7. We anticipated that physician satisfaction, age, gender and diagnosis would significantly moderate the relationship between incongruence and [overall] psychological distress.

2.2.2.3. *Specific research questions for the qualitative part of the research exploring the perspectives of incongruent patients and primary care physicians.*

R2.1. To what extent will patient focus groups enable us to establish the experiences that incongruent patients have when consulting primary care physicians?

R2.2. To what extent will focus groups will help us to identify the implications that gastrointestinal disorders have on the daily life and functioning of patients with incongruent appraisals with physicians?

R2.3. To what extent will physician interviews enable us to identify the resources available for patients with incongruent appraisals with physicians, as well as the most effective treatments for this subgroup of patients?

3. Methods

3.1. Study 1

3.1.1. Design.

The design of the first study was a systematic review which was registered and approved by PROSPERO before conducting data analysis (CRD42019135898). This systematic review was conducted adhering to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines (PRISMA; Moher et al., 2009).

3.1.2. Participants.

3.1.2.1. *Inclusion and exclusion criteria.*

Patient intervention studies had to meet the following criteria in order to be included: (a) Participants were aged ≥ 18 years at baseline (b) diagnosed with a gastrointestinal disorder (c) refer to short-term health educational or psychoeducational intervention. Physician studies were included based on the following: (a) The physician/gastroenterologist treated patients with FGIDs or medically unexplained symptoms and (b) the study referred to educational or training opportunities. All the studies had to be published in English.

We excluded animal studies, meta-analyses, systematic reviews, book chapters, symposiums, specialised psychological interventions, and interventions involving paediatric patients. We believe that the characteristics and contexts of interventions for paediatric patients are distinct enough to warrant a different review.

3.1.2.2. *Search Strategy for Identifying Potential Studies.*

We searched PubMed and Google Scholar from November to February 2018 (see table 2 for an example of the search using PubMed). The search strategies included the following keywords: gastroenterology, health education, psychoeducation, psychosocial interventions,

rumination syndrome, irritable bowel syndrome, functional dyspepsia, patients with somatisation, secondary care, and physicians.

Table 2

The Electronic Search Strategy Performed in PubMed

Search strategy	Results
"Health education in Gastroenterology"	2.391
"Psychoeducation in Gastroenterology"	6
"Psychoeducation for patients with IBS"	3
"Psychoeducation in irritable bowel syndrome"	4
"Health education to improve IBS symptoms"	11
"Health education for patients with Inflammatory and Functional Gastrointestinal Diseases"	14
"Health education for patients with bowel incontinence"	138
"Health education for patients with functional gastroenterology disorders"	53
"Health education for gastroenterologists in secondary care"	7
"Health education for patients with functional somatic symptoms"	38
Psychosocial interventions for patients with functional dyspepsia	3
Psychohealth education for patients with irritable bowel syndrome	3

3.1.3. Data collection and analysis.

3.1.3.1. Selection of Studies.

Initially the studies from PubMed were identified using an online screening database called Rayyan, which allowed for the screening of titles and abstracts. The whole selection process was recorded in a separate excel database accessible to both the doctoral student (AG) and the director (FJEO) of the doctoral thesis. One author (AG) independently screened and recorded the titles and abstracts for selection. Both authors (AG and FJEO) independently assessed the articles that should be selected for the review.

3.1.4. Data extraction.

In this review, we conducted a narrative synthesis for each study. The initial step involved conducting a preliminary synthesis which was implemented by one author (AG).

The preliminary synthesis involved grouping the studies and producing a tabulation of the results which involved the obtainment of the following characteristics of each study: participant demographics, aim of the intervention, intervention length, content and group, outcome and conclusions. The second author (FJEO) reviewed the content of the table and critically assessed each study to ensure it met the inclusion criteria.

3.1.5. Behavioural Change Techniques Taxonomy Coding.

Each of the studies were coded using the Behavioural Change Technique Taxonomy (BCT; Michie et al., 2013). Using a similar technique that has previously been conducted, behavioural interventions were coded if they targeted patient's behaviour or healthcare provider's behaviour (Presseau et al., 2015). One of the authors (AG) individually assessed each intervention using the guidelines and examples adopted in previous studies (Kebede et al., 2017; Michie et al., 2015; Presseau et al., 2015). In the case that interventions were

described as involving the provision of ‘education’ without any additional information, the BCT was coded as information about health consequences and instruction on how to perform the behaviour. Additionally, when interventions were described as providing ‘training’ without further detail, the training intervention was coded as *instruction on how to perform the behaviour*. The interventions were then further assessed by a second author (FJEO). Any discrepancies were resolved through discussion.

3.1.5.1. Assessment of the quality of the methodology.

The Quality Assessment Tool for Quantitative Studies was used to assess the quality of the methodology of each study (Practice, 1998). This tool was used as it assesses the characteristics of both randomized and nonrandomized designs. Both researchers involved in the study evaluated each study for potential bias. Any discrepancies were discussed until a consensus was reached. Raters evaluated the articles on the following characteristics (a) selection bias (b) study design (c) confounders (d) blinding (e) data collection methods and (f) withdrawals and dropouts. Each study received a global rating of either ‘Weak’, ‘Moderate’ or ‘Strong’.

3.2. Study 2

3.2.1. Overall study design.

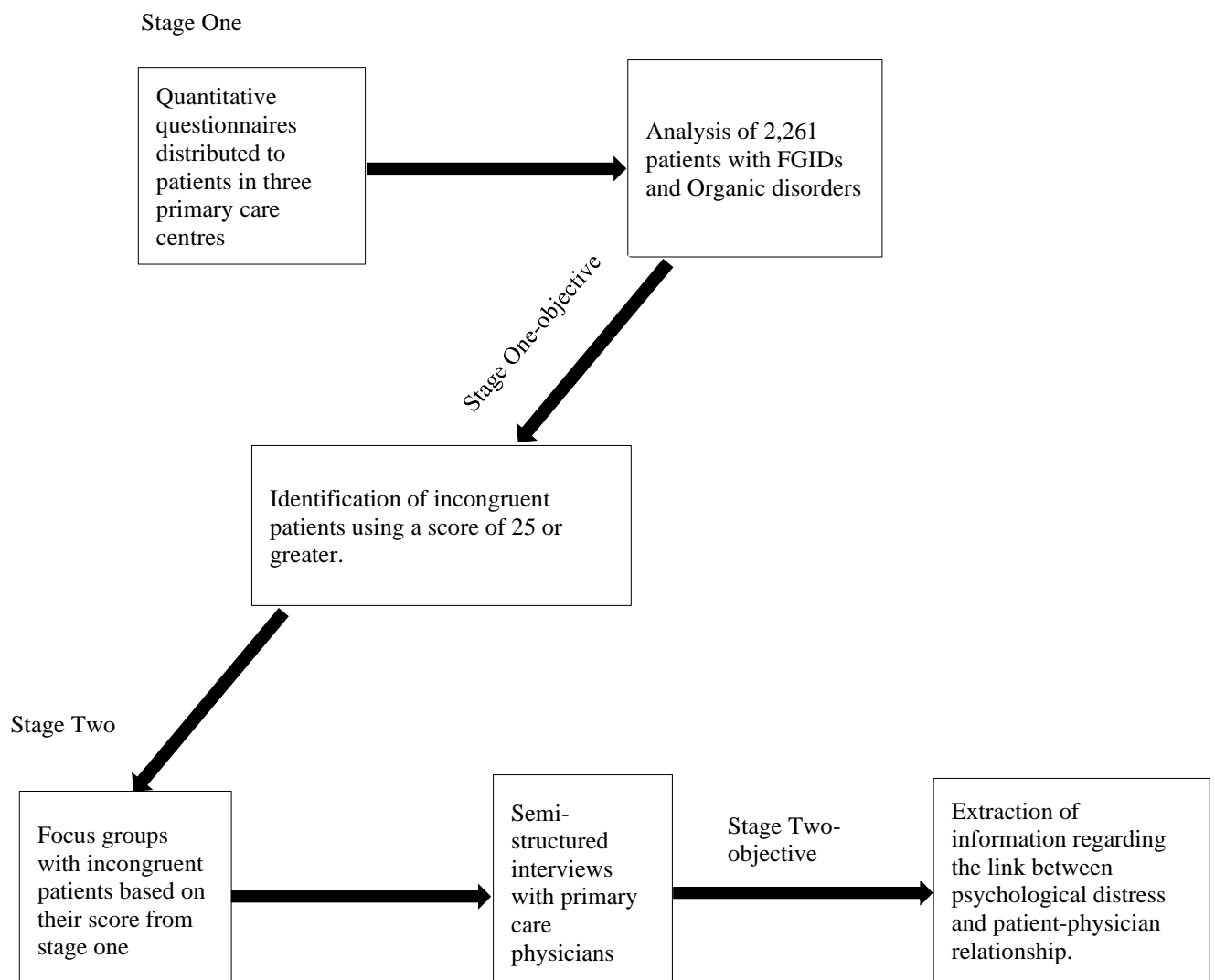
This was a mixed-methods design which was developed to provide a methodological structure capable of eliciting in-depth information regarding the patient-physician relationship.

A sequential approach was adopted as the data retrieved from stage one was analysed in order to identify patients to be included in stage two. Stage one used a quantitative approach and involved two different types of analyses (a) analyses with incongruence as a dichotomous variable and (b) analyses carried out with incongruence as a continuous variable.

Stage two used a qualitative approach involving patients who had been identified as having incongruent views with their consulting physicians, additionally a subset of the physicians that took part in stage one were also invited to take part in stage two. Patients were considered as having incongruent views with their physician if they had obtained a score of 25 or greater, which was identified through the first type of analyses (analyses with incongruence as a dichotomous variable). Figure 4 provides details regarding the purpose of each stage of the study to assist in our overall understanding.

Figure 4

Flow diagram of the research process



3.2.2. Stage One: Quantitative Methodology.

3.2.3. Design.

The first stage of this mixed methods cross-sectional study which involved collecting data from patients regarding their QOL, psychological distress and their level of physician satisfaction.

3.2.4. Sample size estimates.

A sample calculation was conducted accepting an alpha risk of 0.05 and a beta risk of 0.2 in a two-sided contrast. We obtained a result of 485 which considers a conservative correlation coefficient between incongruity and psychological distress of 0.2. This takes into account that 60% of people who consult physicians in primary care do not do so due to a gastrointestinal disorder.

3.2.5. Participants.

Patients were recruited for gastrointestinal disorders from three different centres: Horta primary care centre (PCC), Chafarinas PCC and Sant Andreu PCC. In each PCC, patients were provided with a consultation by the same gastroenterologist throughout the study. All three gastroenterologists involved in the study were well trained in gastroenterology, had at least 5 years of postgraduate experience in gastroenterology and strong links to a referring tertiary care hospital (Vall d'Hebron University Hospital, Barcelona). In order to reduce potential biases, none of the aforementioned gastroenterologists had been involved in the previous research conducted by the team in tertiary care (Eiroa-Orosa et al., 2016; Rodriguez-Urrutia et al., 2016, 2017).

3.2.5.1. Inclusion and exclusion criteria.

Initially all patients were included in the study who were waiting to consult a gastroenterologist in one of the three primary care clinics linked to Vall d'Hebron Hospital.

For the first type of analyses 'incongruence as a dichotomous variable' patients were included if they met the following criteria (a) Aged ≥ 16 (b) diagnosis of an FGID following the Rome IV diagnosis criteria (Drossman, 2016) or a gastrointestinal disorder (c) a sufficient level of Spanish to understand the questions being asked and (d) completed the items from the extended version of the SF-12 which were related to the physical functioning subscale of the original SF-36 questionnaire which would enable us to calculate incongruence (see 3.2.7.5).

For the second type of analyses 'incongruence as a continuous variable' patients were included based on the same criteria (a), (b), and (c) as stated above. However, for the purpose of this type of analyses patients were only included if they had completed the whole of the study. This was defined as having a score for the BSI-18 scale which measures psychological distress, and a score for PDRQ-9 which measures the satisfaction they have with the physician.

Patients were excluded based on the following criteria (a) intellectual disability (b) evidence of a cognitive impairment and (c) low level of Spanish. Regarding exclusion criteria (a) and (b) the expertise of an experienced gastroenterologist was elicited in order to determine whether participants had a history of an intellectual disability or a cognitive impairment. In relation to exclusion criteria (c) patients were assessed on their level of Spanish based on their ability to understand the consent form and provide written consent.

3.2.6. Instruments.

3.2.6.1. *Clinician-rated functional impairment.*

Physicians used the Rome IV criteria in order to determine whether the patient could be classified as having an FGID diagnosis (Drossman, 2016) or another gastrointestinal diagnosis.

The Karnofsky Performance Status Scale (KPS; Karnofsky, 1949) aims to measure the functional status of the patient (see Appendix B). This was completed after the physician had carried out the consultation with the patient. This involves an 11-point scale correlating to percentage values ranging from 100% (no evidence of the disease, no symptoms) to 0% (deceased; Péus et al., 2013). The percentages of the KPS describe three state conditions; Condition A (100-80%) which refers to individuals that are able to carry on with normal activity and which no special care is needed. Condition B (70-50%) refers to individuals who are unable to work, they are able to live at home but may require assistance. Lastly, condition C (40-0%) signifies that the disease is progressing rapidly, the individual is unable to care for themselves and requires hospital or institutional care.

In addition to completing the KPS, gastroenterologists also had to complete a numeric rating scale which was used to measure their subjective view of how the consultation had gone with the patient. This involved asking them the question 'In your opinion, how did the consultation go with the patient' and providing a scale ranging from 0 'very bad' to 100 'very good' (see Appendix B).

3.2.7. Psychosocial assessments.

The following information was obtained from each patient which involved collecting data regarding the patients' demographics, quality of life, psychological distress and physician satisfaction (see Appendix C for a full list of the instruments that were administered).

3.2.7.1. Demographics.

A questionnaire consisting of seven items related to gender, age, marital status, country of origin, educational qualifications, employment status, type of consultation (i.e., if this was their first consultation or a follow-up) and the reason for the consultation.

3.2.7.2. The Short-Form Health Survey (SF-12).

The SF-12 is a health-related quality of life questionnaire. An extended version of the SF-12 health related QOL questionnaire was administered to patients in this study as we included additional items which belonged to the original '36-item Short-Form Health Survey' (SF-36). This was in order to be able to assess incongruence between patients and physicians. Thus, the current questionnaire contained 20 items; eight of the items belonged to the original SF-36 (see Appendix C items 2,4,6,7,8,9,10 and 11) and the remaining 12 items were from the SF-12 questionnaire (Schmidt et al., 2012; Ware & Sherbourne, 1992).

The original SF-12 involves choosing between two and six responses on a Likert scale. This questionnaire is formed by eight dimensions: General Health (GH), Physical Functioning (PF), Role Physical (RP), Role Emotional (RE), Social Functioning (SF), Bodily Pain (BP), Mental Health (MH) and Vitality (VT). For example, the first item which was related to General Health involved the following statement 'In general would you say your health is...' in which the respondent had to choose between five responses ranging from 5 (excellent) to 1 (poor). All raw scores were transformed and standardised to a scale ranging from 0-100. Physical and mental health subscale scores were then produced.

The physical health score consisted of six items with the following dimensions: PF; RP; BP and GH. Similarly, the mental health score also included six items and involved the following dimensions: VT, SF, RE and MH. Higher scores indicated better health state, for

example higher scores on functioning and pain items signified both better functioning and freedom from pain. The Cronbach alpha for overall physical health ($\alpha=.832$) and for overall mental health ($\alpha=.798$) indicate relatively high consistency.

3.2.7.3. *The Brief Symptom Inventory (BSI-18).*

The BSI-18 is a shortened version of the Symptom Checklist-90 Revised Scale (SCL-90-R; Derogatis, 1994). The BSI-18 is a brief psychological self-report symptom scale with a total of 18 items (Andreu et al., 2008). Respondents were asked to indicate on a Likert scale ranging from 0 (not at all) to 4 (very much) to what extent they have experienced symptoms in the last week.

The symptoms were related to three dimensions; Somatisation, Depression and Anxiety (six items per dimension). The first dimension is 'Somatisation' which refers to the distress caused by the perception of bodily dysfunction and the focus on symptoms arising from gastrointestinal and other physiological systems. For example, respondents were asked to what extent they had experienced complaints such as 'Faintness or dizziness' in the last week. The second dimension is 'Depression' which refers to symptoms of disaffection and dysphoric mood such as loss of hope or suicidal ideation. For instance, the respondent had to indicate to what extent they had 'Felt lonely' in the last week. The third dimension 'Anxiety' refers to symptoms of nervousness, tension, motor restlessness, apprehension, and panic states. For example, patients had to indicate to what extent they had felt 'so restless they can't sit still'. Lastly the overall psychological distress score, commonly referred to as 'General distress', was also provided and refers to the total score of all of the dimensions. This ranges from 0 to 72, higher scores reflect greater distress. The Cronbach alpha for 'General distress' ($\alpha=.919$) shows strong internal consistency.

3.2.7.4. *The Patient-Doctor Relationship Questionnaire (PDRQ-9).*

The PDRQ-9 is a brief measure that assesses the patient-doctor relationship in primary care settings (Martín-Fernández et al., 2010). This scale is composed of nine statements in which the patient is required to make a subjective assessment of the relationship that they have with the primary care physician (Aloba et al., 2015). Each response is chosen from a Likert scale of five categories ranging from 1 (totally disagree) to 5 (totally agree). The scores can range from a minimum of 9 to a maximum of 45, higher scores indicate that the patient has a more positive view regarding the relationship they have with their doctor (Aloba et al., 2015). The Cronbach alpha for the PDRQ-9 ($\alpha=.946$) indicates strong internal consistency.

3.2.7.5. *The method involved to assess incongruence between the clinician's assessment and the patients' self-reported functionality.*

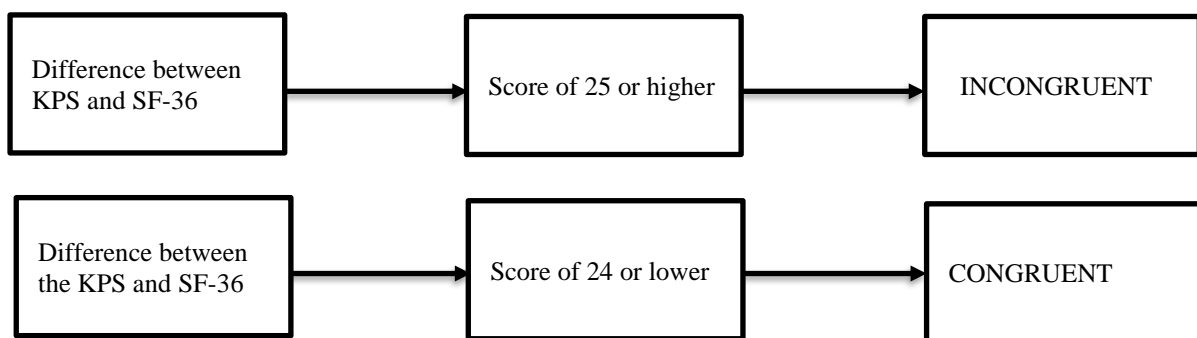
The first type of analyses 'incongruence as a dichotomous variable' used the same premise that was adopted by a previous study (Rodríguez-Urrutia et al., 2017) in which incongruence was identified as having a value of 25 or greater on the difference between the KPS and the physical functioning subscale of the SF-36 (see Appendix C, items 2-11). As previously mentioned, the raw scores from the SF-36 physical functioning subscale were standardised into a scale ranging from 0-100 which enabled to calculate the difference. Physical functioning was defined as the degree to which health limits the ability to carry out physical tasks such as activities that require a moderate amount of physical effort (e.g., moving a table) to activities that are considered to be more intense (e.g., lifting weights; Alonso, 1996).

As illustrated in figure 5, positive numbers of 25 or above were seen as a sign of incongruence as it meant that the physician believed that the patient had a much better physical functionality than they actually did. Scores of 24 or less, were seen as a sign that the patient and physician had congruent (or more similar) views regarding the patient's physical

functionality. Scores close to zero indicated absolute congruence (i.e., the patient and the physician had approximately the same perception regarding the patient's physical functioning). This cut-off point was selected as a means of identifying patients with lower levels of physical functioning that could be explained by the gastrointestinal disorder. Additionally, it is expected that some differences would be found between patients and physicians. Therefore, placing the cut-off point at 25 provided enough margin to be able to identify patients with higher levels of incongruence rather than just detecting patients who had slightly different perceptions of their physical wellbeing than the physician.

Figure 5

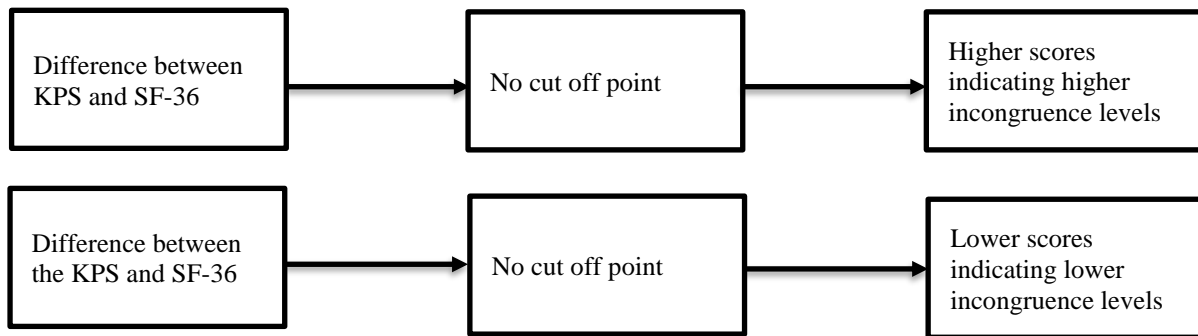
Classification of the dichotomous variable 'incongruence'



The second type of analyses 'incongruence as a continuous variable' was based on previous literature (Rodriguez-Urrutia et al., 2016). As illustrated in figure 6, incongruence was also defined as the difference between the KPS and the SF-36 physical functioning subscale, however no cut-off point was implemented for this type of analyses. Therefore, as stated previously scores close to 0 indicated absolute congruence between the clinician and patient's perception regarding the patient's physical functioning. Higher scores indicated higher levels of incongruence, whereas lower scores indicated the opposite.

Figure 6

Classification of continuous variable 'incongruence'



3.2.8. Procedure.

The first part of the study was conducted between May 2018 and July 2018 in three PCCs in Barcelona. Three trained evaluators collected the data and each of them were allocated to a specific PCC, which they remained in until the end of the study.

Before collecting patient information, the evaluator ensured that the patient was provided with information regarding the objectives, the benefits, the procedure of the study and data protection information. The patient was reassured that the contact details that they provided for the study would remain completely confidential. The patients were then provided with the consent form and were asked to sign this before beginning the study.

The first part of the study involved the administration of the sociodemographic questions. Once the patient had completed this, they were then asked to complete an extended version of the SF-12 and the BSI-18. This first process took approximately 15-20 minutes and was conducted before the consultation with the physician.

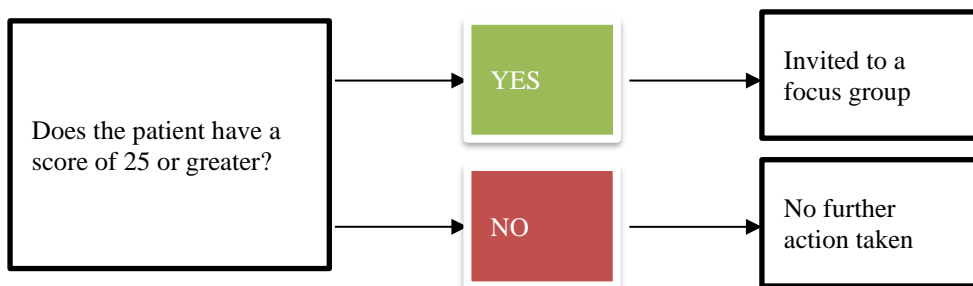
After the consultation with the physician, patients were asked to complete the final measure which was the PDRQ-9. In our study, the patient completed the PDRQ-9 straight after the consultation with the physician. Therefore, the items referred specifically to the consultation they had with the physician "*The doctor has helped me*". This process took

approximately 5-10 minutes to complete. The three physicians that were involved in the study would ensure that for each patient they had seen that they would record two numbers: a number from the KPS and a number from the visual analogue scale.

After developing this part of data collection through questionnaires, focus groups were developed with patients so that they could explain in their own words the discrepancies in the vision of functionality and quality of life. These focus groups have been analysed using thematic analysis and the results from this will be discussed in more detail below in section. A summary of the procedure can be seen below in figure 7.

Figure 7

A summary of the selection procedure for stage two



3.2.9. Stage Two: Qualitative Methodology.

3.2.10. Research design overview.

The second part of the study used a qualitative research collection method which was based on thematic content analysis. Content analysis was selected because it uses a systematic process of identifying patterns across qualitative data. Additionally, the development of categories or themes allows for a broad description of the phenomenon. As recommended by recent literature (Shaw et al., 2019) we adhered to the American Psychological Association's guidance for reporting qualitative research Journal Article Reporting Standards for Qualitative Research (JARS-Qual; Levitt et al., 2018).

3.2.11. Study participants.

3.2.11.1. *Researcher description*

The research team consisted of a doctoral psychology student, a trained therapist and the lead investigator. The first author (AG) is a doctoral candidate with over four years of experience in research and is currently on the ‘Clinical and Health Psychology’ doctoral programme. The second author (CGI) is a qualified therapist who has completed the Master’s in ‘General Health Psychology’ and has had experience treating a number of different patients, such as those with addictions. The final author (FJEO) is an experienced researcher specialising in strategies for mental health users and professionals. Furthermore, FJEO has previously conducted research related to patients with similar diagnoses in tertiary care settings. For instance, FJEO has analysed data related to patients with functional gastrointestinal disorders. The diverse backgrounds of the team were seen as a strength in the overall execution of the data collection process. The experience and expertise of the third author (FJEO) in conducting health research allowed for greater accuracy in the analysis of the data.

3.2.12. Participant recruitment.

3.2.12.1. *Participant selection*

Purposive sampling was used to recruit patients for the current research. As mentioned in the first stage of study 2, sociodemographic data was initially collected at one of three PCCs in Barcelona. Patients were eligible to take part if they met the following inclusion criteria (a) They had been outpatients consulting for gastrointestinal disorders from May to July 2018 (b) They were patients who were at least 16 years old or above (c) fluent in Spanish or had a high enough level to be able to follow the conversation in the focus group (d) They were capable of providing written informed consent (e) They had a diagnosis of a gastrointestinal disorder

based on the Rome IV criteria or had a gastrointestinal disorder (f) They had a score of 25 or higher and thus were considered as being incongruent.

Patients were excluded if they met the following criteria (a) The patient could be considered as having congruent views with the physician (b) cognitive impairment and/or (c) an intellectual disability.

All the physicians involved in this section of the research treated patients with gastrointestinal disorders and were linked to Vall d'Hebron Hospital. Three of the physicians were gastroenterologists (two of which had been involved in the first stage of the research) and one was an experienced consultation-liaison psychiatrist. The psychiatrist had a background in functional and neurological digestive disorders.

3.2.12.2. Recruitment process.

A trained therapist (CGI) invited eligible patients either by email or phone only if they had specified their interest in being contacted. Patients were informed that the main objective of the focus group was to 'deepen knowledge of factors that may be contributing to the level of agreement between patients and physicians and how these factors could be influencing functional gastrointestinal disorders'. Patients were then invited to take part in the patient focus groups at the primary care centre where they were registered. Physicians were contacted by email to take part in the semi-structured interviews by FJEO.

A total of 87 patients initially signed up to attend the focus groups, the final sample composed of 52 patients. Patients did not attend due to a variety of reasons such as work commitments, health related reasons, they were out of the area or they had medical appointments. Data collection was stopped once all eligible patients had been contacted. Data saturation was achieved in the analysis stage based on the principles outlined by the 'Inductive

Thematic Saturation Model' (Saunders et al., 2018) This refers to reaching saturation once there is no emergence of new codes or themes.

3.2.13. Data collection

3.2.13.1. Focus groups with patients.

The trained therapist (CGI) and PhD student (AG) conducted the focus groups. The principal investigator (FJEO) carried out the physician interviews. Based on the literature, open ended discussions and semi-structured interviews were encouraged in order to yield data which reflected the patient's and physicians' subjective views rather than those of the authors (Lasch et al., 2010).

Focus groups were carried out in three PCCs, the same as previously mentioned in the stage one, between September and October 2018. After gaining written informed consent from each individual patient, an introduction was given lasting between 5-10 minutes. The focus group discussions were conducted in a flexible format and involved questions focusing on the extent to which their health status had affected their daily life (e.g., social support, quality of life). The second half aimed to obtain their opinion regarding the health system and the contact that they have had with physicians (i.e., access to doctors, type of physician communication they had received). Before ending the session, patients were given approximately 10-15 minutes to ask questions and provide their views on other topics related to their illness. Each group involved between four and nine patients and lasted approximately two hours, with an average time of 60 minutes. The discussions were audio-recorded with the consent of the patient in order to be transcribed and analysed at a later date. Patients were reassured that personal information would be omitted in order to ensure that individual patient's views were not identified. Patients were also informed that recordings would be destroyed once they had

been transcribed and that transcripts would not include any personal data. In the case that they have mentioned names or any other personal data, these will not be transcribed.

3.2.13.2. Interviews with physicians.

The semi-structured individual interviews were conducted at Vall d'Hebron Hospital between October and November 2018. The interviewer (FJEO) interviewed four physicians: three gastroenterologists and one consultation-liaison psychiatrist.

Before beginning the interviews, physicians were provided with an information sheet which outlined that the interview would involve a discussion regarding their relationship with gastrointestinal patients. Written informed consent was obtained as the discussions were audio-recorded in order to be transcribed at a later date. Physicians were informed that personal information would be omitted in order to ensure confidentiality and anonymity of the physician.

The one-to-one interviews lasted on average 60 minutes and involved a total of six open ended questions. As demonstrated in table 3, the questions covered the following themes: (1) Implications of the disorder (2) ease of the diagnosis (3) explanation of the diagnosis (4) acceptance of symptoms (5) characteristics of the patients and (6) mental health services.

Table 3

A Summary of the Physician Themes and Interview Questions

Physician Themes	Interview questions
Implications of the disorder	We have seen that your work involves working with patients with different types of disorders. What implications do the characteristics of functional, motor, inflammatory disorders have on your work?
Ease of the diagnosis	Would you say that it is easier for you to make the diagnosis or develop an intervention with one type of patient than with another?

Physician Themes	Interview questions
Explanation of the diagnosis	Do you explain the diagnosis differently according to the characteristics of the patient?
Acceptance of symptoms	Have you noticed that patients with certain diagnoses are less able to accept their symptoms?
Characteristics of the patient	Depending on the characteristics of the patient, do you act differently to what you have noted down in the medical record?
Mental health services	What benefits could a collaboration with mental health services bring you?

3.2.14. Stage One: Quantitative Analysis.

Two different types of analyses were carried out for study 2 stage one. The first analyses conducted was referred to as ‘analyses with incongruence as a dichotomous variable’. Patients were only included in this type of analyses if they had completed at least the physical functioning subscale of the SF-36, which was essential to be able to calculate incongruence.

The second type of analyses, referred to as ‘analyses carried out with incongruence as a continuous variable’ involved including only patients who had completed the BSI-18 scale (i.e., had an overall score for psychological distress) and the PDRQ-9 (i.e., had an overall score for physician satisfaction). Patients who had missing data for either one of these scales were excluded from the analyses. The BSI-18 scale was an important component as psychological distress was the dependent variable in our study. The completion of the PDRQ-9 was relevant as it was the final scale given to patients and therefore, we could ascertain that the patient had completed the rest of the measurements.

All statistical analyses were conducted with the Statistical Package for the Social Sciences (SPSS) v.25.

3.2.14.1. Normality tests.

Normality checks were conducted for each of the outcome variables: incongruence, overall psychological distress and physician satisfaction scores. Histograms and p-p plots were first visually assessed and were not found to be normally distributed. The skewness and kurtosis in each of the outcome variables was then analysed: incongruence (skewness= .824, kurtosis= .201), overall psychological distress (skewness =1.195, kurtosis= 1.023) and physician satisfaction scores (skewness= -.1.221, kurtosis =.599). All the skewness and kurtosis values fell into the acceptable range of -2 to +2 (George, 2011). Whilst the data was not initially considered to be normally distributed, given the large sample and the skewness and kurtosis values we proceeded with parametric testing.

Table 4

Statistical analyses with incongruence as a dichotomous variable

Hypotheses	Analyses implemented
H1.1. We expected to find differences for the variable incongruence. In other words, we anticipated that there would be statistically significant differences between patients with incongruent and congruent appraisals for all of the sociodemographic variables. We predicted that patients with incongruent appraisals with physicians would most likely be older, female, have lower levels of education, less likely to be married or in a stable relationship and be in employment than patients with congruent appraisals with physicians.	Parametric test: <i>t</i> -test Non-parametric test: Chi-square
H1.2. We predicted higher [overall] psychological distress scores and for each of the different subscales (e.g., somatisation, depression and anxiety) for patients with incongruent appraisals with physicians compared to those with congruent appraisals.	Parametric test: <i>t</i> -test

Hypotheses	Analyses implemented
H1.3. We predicted higher [overall] psychological distress scores and for each of the different subscales (e.g., somatisation, depression and anxiety) for patients with a functional gastrointestinal diagnosis compared to patients with an organic diagnosis.	Parametric test: <i>t</i> -test
H1.4. We anticipated higher physician satisfaction scores for patients with congruent appraisals with physicians compared to those with incongruent appraisals.	Parametric test: <i>t</i> -test
We also predicted higher physician satisfaction scores for patients with an organic diagnosis compared to patients with a functional gastrointestinal diagnosis.	
H1.5. We expected statistically significant differences in psychological distress scores based on the type of appraisal (incongruent v congruent) that the patient had with their physician <i>(this hypothesis attends to the first main effect)</i>	Parametric test: General linear models
We expected statistically significant differences in psychological distress scores based on the diagnosis (functional v organic) of the patient <i>(this hypothesis attends to the second main effect).</i>	
We expected to find statistically significant differences in psychological distress scores based on the type of appraisal that the patient had with their physician and the patient's diagnosis <i>(this hypothesis relates to the interaction effect).</i>	

Table 5

Statistical analyses with incongruence as a continuous variable

Hypotheses	Analyses implemented
H2.1. From the sociodemographic variables we expected to find a statistically significant difference between the mean ages of patients who completed the study compared to those who did not complete the study. We also expected to find differences between the two groups regarding other sociodemographic variables.	Parametric test: <i>t</i> -tests Non-parametric test: Chi-square

Hypotheses	Analyses implemented
<p>H2.2. We expected that incongruence scores would be positively correlated with psychological distress. We also anticipated that incongruence would be negatively correlated with the mental health component score.</p>	<p>Parametric test: Pearson correlations.</p>
<p>H2.3. We expected higher incongruence scores for patients with a functional gastrointestinal diagnosis than patients with an organic diagnosis.</p>	<p>Parametric test: <i>t</i>-tests</p>
<p>We also predicted lower QOL for patients with a functional gastrointestinal diagnosis than patients with an organic diagnosis.</p>	
<p>H2.4. We anticipated that incongruence would be negatively correlated with physician satisfaction.</p>	<p>Parametric test: Pearson correlation</p>
<p>H2.5. We expected that female patients would have higher incongruence scores, [overall] psychological distress, as well as for each of the different psychological distress subscales than male patients. We expected that female patients would have lower quality of life than male patients. We also explored whether female patients would have lower physician satisfaction than male patients.</p>	<p>Parametric test: <i>t</i>-tests</p>
<p>We expected that age would be positively correlated with incongruence, [overall] psychological distress, its subscales and physician satisfaction. We predicted that age would be negatively correlated with QOL.</p>	<p>Parametric test: Pearson correlation for age</p>
<p>H2.6. We predicted that the variables incongruence, age, gender, physician satisfaction and diagnosis would significantly predict [overall] psychological distress.</p>	<p>Parametric test: Multiple regression model</p>
<p>H2.7. We anticipated that physician satisfaction, age, gender and diagnosis would significantly</p>	<p>Parametric test: Moderation models</p>

Hypotheses	Analyses implemented
moderate the relationship between incongruence and [overall] psychological distress.	

3.2.15. Stage Two: Qualitative Analysis

The qualitative data was digitally audio-recorded and transcribed verbatim by a trained therapist (CGI). SoundScriber was used to aid us in the transcription of the audio files which involved writing word for word what was stated by the patient or physician. An inductive thematic analytical approach was used to identify repeated patterns of meaning referred to as themes (Braun & Clarke, 2006). Steps to identify the main themes were followed using the ‘phases of thematic analysis’ as recommended in the literature (Braun & Clarke, 2006).

ATLAS.ti software was used to assist with coding and the development of themes. This qualitative analysis software enabled us to code the transcriptions by annotating words which was used to synthesize pieces of text. In order to develop the themes, a trained therapist (CGI) first familiarised herself with the data and identified common themes, patterns and narratives through the analysis of words or fragments of text. Themes were then checked and reviewed by a PhD student (AG) and adapted accordingly in order to ensure accuracy of the themes. The final themes were verified by the principal investigator of the research (FJEO). All themes were then agreed upon by CGI, AG and FJEO. All identifiable information was anonymised ensuring that no individual patient could be identified. The proportion of codes that refer to the themes most often presented are demonstrated in the results section in table 17 and table 18.

3.2.16. Ethical considerations.

All patients in study 2 were asked to sign and provide written consent before taking part in the research. Patients were also provided with information regarding the right to access their personal data, modify or delete it. Additionally, patients were informed that their participation was completely voluntary, that if they decided to decline that they would continue

receiving medical care from their consulting physician and that this would in no way affect the relationship that they have with the medical team caring for them.

In regard to the research team, all evaluators gave the hard copies of the data to the PhD student who then stored this in a locked and secure location. The digitalised copies of the data are password protected and can only be accessed by the principal investigator. Lastly, the database has been anonymised, with only a unique identification number being allocated to each individual patient (e.g., 2018_05_14_01).

The study was approved by the Bioethics Commission from the University of Barcelona (IRB00003099) and by the Ethics Committee from Vall d'Hebron University Hospital (PR(AG)92/2018).

4. Results

4.1. Study 1

4.1.1. Study selection.

As presented in figure 8, the database search provided 6,141 related studies, of which 33 articles were potentially relevant. After screening the full text, a total of 25 were excluded due to not meeting the inclusion criteria. A total of eight articles were considered to be suitable for this review (Bengtsson et al., 2006; Berens et al., 2018; Håkanson et al., 2012; Joyce et al., 2017; Labus et al., 2013; Ringström et al., 2009; Schaefer et al., 2013; Warner et al., 2017).

4.1.1. Overall summary of the intervention findings.

Table 6 presents a summary of the following characteristics (a) Participant demographics (b) intervention length, content and groups (c) outcome and (d) conclusions for each individual study that was included in the systematic review. The main findings have been split into the following two headings: ‘short-term educational interventions’ and ‘psychoeducational interventions’.

The results from the physician interventions have been discussed in greater detail (see page 65). As both studies were qualitative studies, the findings have been placed under the subheading ‘qualitative interviews with physicians’.

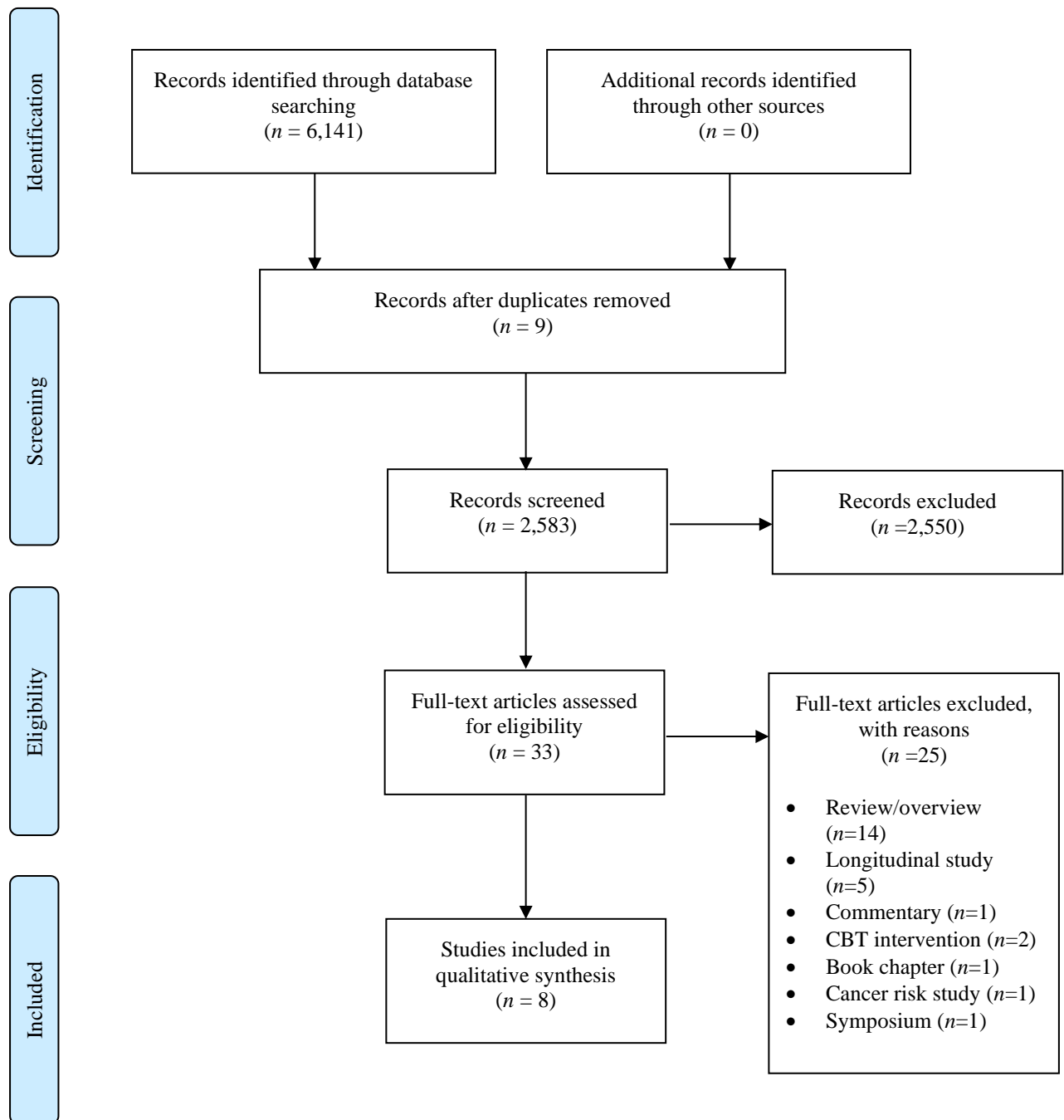
Figure 8*Flow diagram of the study selection process*

Table 6*Overview of the Studies Included in the Systematic Review*

Author	Participant demographics	Intervention length, content and groups	Outcome	Conclusions
Bengtsson, M., Ulander, K., Börgdal, E. B., Christensson, A.-C., & Ohlsson, B. (2006).	Patients with irritable bowel syndrome (IBS)	29 women with IBS participated in a programme of instruction. The women also completed the Gastrointestinal Symptom Rating Scale and the Psychological General Well-being Index	Twenty-three of the women completed the questionnaires 12 months after the course. There were improvements in abdominal pain, vitality, as well as a reduction in the number of consultations to physicians and dieticians.	Information related to the disease may help women with IBS to perceive less pain and more vitality and thereby experience a better quality of life.
Berens, S., Stroe-Kunold, E., Kraus, F., Tesarz, J., Gauss, A., Niesler, B., ... Schaefert, R. (2018)	Patients with IBS	294 patients (220 had IBS; 144 diagnosed with SAD). 30 patients consented to participate (group intervention n=16) and the wait-listed control condition (n=14).	The group intervention was not significantly superior to the wait-listed control condition. Effect size for between-groups at the end of the treatment (post) was moderate.	The integrative group intervention for IBS proved to be acceptable and feasible in an interdisciplinary tertiary care setting.
Håkanson, C., Sahlberg-Blom, E., Ternstedt, B.M., & Nyhlin, H. (2012).	Patients with IBS	<ul style="list-style-type: none"> • 31 participants • Focus group interviews 	Four patterns were found to be important; a) Being part of a safe community	The combination of reciprocal sharing of experiences and the provision of professional scientific knowledge

Joyce, E., Cowing, J., Lazarus, C., Smith, C., Zenzuck, V., & Peters, S. (2017).	Medical educators from different UK medical schools	28 medical educators from thirteen different UK medical schools Semi-structured interviews	<p>b) Learning about oneself through others c) Understanding and controlling the body and illness as a whole d) Being outside of the community</p> <p>Barriers to implementing functional syndromes (FS) training are beliefs about the complexity of FS, tutors' negative attitudes towards FS, and FS being perceived as a low priority.</p> <p>They recommended that students learn about FS through managed exposure but only if the tutors' negative attitudes and behaviours are also addressed.</p>	<p>during the patient education programme together contributed to a readiness to improve well-being in everyday life.</p> <p>Negative attitudes towards FS by educators prevents designing and delivering effective education There is a need to implement FS training, but recommendations are multifaceted.</p> <p>There needs to be an increase in liaison between students, patients and educators in order to develop more informed and effective teaching methods for trainee physicians regarding FS</p>
Labus, J., Gupta, A., Gill, H. K., Posserud, I., Mayer, M., Raen, H., ... Mayer, E. A. (2013).	Patients with IBS	<ul style="list-style-type: none"> 69 patients were randomised to the intervention (n=34) or to the wait-list control group (n=35) 	Patients in the intervention showed significant improvement on gastrointestinal symptom severity, visceral sensitivity, depression and	A brief psycho-educational intervention is effective in changing cognitions and fears regarding the symptoms of IBS and these changes are linked to

Ringström, G., Störsrud, S., Lundqvist, S., Westman, B., & Simrén, M. (2009).	Patients with IBS	12 patients (5-7 in each group) Five different health care professionals were involved in the education Six weekly two hour sessions	QOL post-intervention and these were maintained at the 3-month follow-up. Patients were satisfied with the IBS school. The gastrointestinal symptoms, health related quality of life and knowledge about IBS improved significantly after the education.	improvements in symptoms and quality of life. This study indicated that an IBS school seems to be a useful method of meeting the needs of patients and providing them with information about IBS and could help to improve the patients' gastrointestinal symptoms, health related quality of life and knowledge about IBS.
Schaefer, R., Kaufmann, C., Wild, B., Schellberg, D., Boelter, R., Faber, R., ... Herzog, W. (2013).	Patients with medically unexplained symptoms	304 patients (170 intervention group; 134 in the control group). 10 weekly group sessions and 2 booster meetings	There was a significant reduction in somatic symptom severity at 6 months, but which lacked significance at 12 months. Between group effects indicated less health anxiety, less psychosocial distress and fewer GP consultations.	Collaborative group interventions led to meaningful improvements in mental but not physical quality of life. This has the potential to bridge the gap between general practice and mental health care.

Warner, A., Walters, K., Lamahewa, K., & Buszewicz, M. (2017)	Physicians working with patients in secondary care	20 consultant and training-grade physicians working in cardiology, gastroenterology, rheumatology and neurology In-depth interviews with 20 physicians; 11 consultants and 9 specialty trainees.	There was considerable variation in how the physicians approached patients who presented with medically unexplained symptoms. Physicians reported little or no formal training in how to manage these types of patients. Physicians described learning from their own experience and from senior role models.	There is a need for serious consideration as to how the management of patients with medically unexplained symptoms are included in medical training and in relation to the planning and delivery of services.
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4.1.2. To what extent can a short educational intervention improve quality of life and symptom severity? (R1.1).

Few effective short-term educational programmes were found for patients with functional gastrointestinal disorders and medically unexplained symptoms. From the studies identified, it was found that the most effective method for improving quality of life and symptom severity was group based educational programmes combining lectures and practical sessions.

4.1.2.1. Short-term educational programmes.

The first study used a course of instruction which involved an educational programme consisting of four lectures. The findings showed that when providing information to woman with IBS on topics, such as medical care and stress management, that they perceived less pain, achieved more vitality, and experienced a higher quality of life (Bengtsson et al., 2006). Improvements were also found from baseline to 12-month follow-up in abdominal pain and vitality.

The second study showed that after a five-day patient educational programme that overall symptom severity of patients with IBS was reduced (Håkanson et al., 2012). The participants scored their symptoms and the overall influence of IBS on everyday life as being significantly lower after the education programme. Additionally, improvement in symptom severity also led to better coping strategies (Håkanson et al., 2012).

In a similar study conducted by Ringström and colleagues (2009) a six week IBS school was implemented based on the self-efficacy theory. There was a statistically significant reduction in gastrointestinal symptom severity, which was indicated with lower scores on the IBS severity scoring system after three and six months (Ringström et al., 2009). Additionally,

statistically significant improvements were found in HRQOL which were found on several domains of the SF-36, as well as on both the physical and mental summary scores after an educational intervention (Ringström et al., 2009).

Furthermore, one study used a collaborative group intervention for patients with medically unexplained symptoms. There were between-group effects for improvement in symptom severity that lasted 12 months, but the effect lacked significance. Additionally, there were between-group effects for the mental domains of vitality and emotional role functioning and among the SF-36 physical domain of the general health perceptions. Patients in the intervention group also reported significantly greater improvements in mental quality of life than the controls at 12 months (Schaefer et al., 2013).

4.1.2.2. Psychoeducational interventions.

The study by Berens et al (2018) involved a multicomponent group therapy intervention. This involved integrating and combining evidence based psychodynamic therapy with psychoeducation, gut-directed hypnotherapy, and treatment elements from cognitive behavioural therapy in a disorder orientated manner. The disorder orientation was provided by introducing the brain-gut axis as a bio-psycho-social explanatory model for FGIDs. The results from the 'Irritable Bowel Severity Scoring System' (IBS-SSS) showed that IBS symptom severity improved within the intervention group (Berens et al., 2018).

The study by Labus et al (2013) aimed to evaluate the effectiveness of a psychoeducational intervention on IBS symptoms. Sixty nine IBS patients were randomised to an intervention or wait-list control group. Patients who took part in the intervention showed significant improvements in gastrointestinal symptom severity, visceral sensitivity, depression, and quality of life post intervention. Additionally, patients who received the intervention demonstrated higher QOL scores than controls at the end of the study, which was also the case

during the three month follow-up. Interestingly, the intervention did not lead to higher levels of QOL for those patients with high baseline levels on the ‘Irritable Bowel Syndrome Quality of Life’ (IBS-QOL) questionnaire. Whereas for patients who were classified as having an ‘average’ level of QOL, a lower score for severity in symptoms was found in the intervention group than in the control group (Labus et al., 2013).

4.1.3. To what extent can a short-educational intervention or training activity change the beliefs and attitudes that they have towards this subgroup of patients? (R1.2).

Few studies have outlined training opportunities and educational interventions for physicians working with this subgroup of patients. A patient-centred approach and managed patient exposure were found to be the most effective methods of changing beliefs and attitudes.

4.1.3.1. *Qualitative interviews with physicians.*

During the interviews conducted with PCPs and gastroenterologists common attitudes were found regarding the management of patients. For example, some of the key findings were that most patients with IBS should and can be managed by PCPs and that IBS patients require a patient-centred approach.

Whilst variations were found in the approach used during consultation, both primary and secondary clinicians emphasised the importance of good communication between clinicians and patients, as well as the importance of providing the patient with a clear explanation of their IBS symptoms. Regarding the development of their personal approach towards managing these patients, many physicians spoke of learning by example from different colleagues, whilst others spoke of learning from their own mistakes. A reoccurring theme from

nearly all the physicians interviewed was that they had received little or no teaching during their training and many relied on informal ‘on the job’ experience (Warner et al., 2017).

In a study conducted with medical educators, some solutions and recommendations were outlined that could address training limitations. The first recommendation was to address negative attitudes and behaviour by focusing on the tutors’ understanding regarding patients with medically unexplained symptoms, as well as sharing good practice and supporting trainee physicians to think critically. By doing so, educators have the chance to help trainee physicians understand patient’s frustrations and are less likely to internalise the negative attitudes related to this subgroup of patients. The second recommendation outlined the importance of encouraging students to learn through ‘managed patient exposure’. This involves providing trainee physicians with an insight into the experiences of the patients and carers. This could convey to the trainee physician the impact that these disorders have on the patient, as well as the most appropriate method of working with these types of patients. For instance, one recommendation provided involved evidence based guidelines (Joyce et al., 2017).

4.1.4. Content analysis of interventions using the ‘Behavioural Change Techniques Taxonomy’.

As seen in table 7 each of the interventions had addressed at least one of the BCT categories. Of the eight studies included in the current systematic review, six had implemented clear BCTs. The two physician studies had addressed the need for training opportunities; however, they did not provide details outlining the intervention. As a result, both were coded as ‘instruction on how to perform the behaviour’.

Table 7*Content Analysis of the Interventions using the Behavioural Change Techniques**Taxonomy*

BCT's identified (n=8)	Bengtsson et al (2006)	Berens et al (2018)	Håkanson et al (2012)	Joyce et al (2017)	Labus et al (2013)	Ringström et al (2009)	Schaefer et al (2013)	Warner et al (2017)
Antecedents (12.6)	■		■		■	■	■	
Feedback and monitoring (2.3)								
Goals and planning (behavior) (1.1)							■	
Goals and planning (outcomes) (1.3)		■						
Natural consequences (5.3)			■					
Shaping knowledge (4.1)				■	■	■		■
Social support (3.3.)		■	■				■	

4.1.5. Quality ratings of the included studies.

Table 8 demonstrates the methodological quality of the studies across a range of dimensions (Practice, 1998). Overall, one study received a strong global rating (Schaefer et al., 2013), two studies received a moderate global rating (Berens et al., 2018; Labus et al., 2013) and five studies received a weak global rating (Bengtsson et al., 2006; Håkanson et al., 2012; Joyce et al., 2017; Ringström et al., 2009; Warner et al., 2017).

Table 8*A Summary of the Quality Ratings of the Included Studies*

Source	Global Rating	Selection Bias	Study Design	Confounders	Blinding	Data Collection Method	Withdrawals and Dropouts
Bengtsson et al, 2006	Weak	Moderate	Moderate	Weak	Weak	Strong	Strong
Berens et al, 2018	Moderate	Moderate	Strong	Strong	Weak	Moderate	Strong
Hakanson et al, 2012	Weak	Moderate	Weak	Weak	Weak	Weak	N/A
Joyce et al, 2017	Weak	Strong	Weak	Weak	Weak	Weak	N/A
Labus et al, 2013	Moderate	Moderate	Strong	Strong	Weak	Moderate	Moderate
Ringström et al, 2009	Weak	Moderate	Moderate	Weak	Weak	Strong	Strong
Schaefer et al, 2013	Strong	Moderate	Strong	Strong	Strong	Strong	Strong
Warner et al, 2017	Weak	Moderate	Weak	Weak	Weak	Weak	N/A

4.2. Study 2

4.2.1. Overall sociodemographic and psychosocial characteristics.

The sample collected was composed of 2,261 patients ranging from 16-96 years of age. Using the guidance provided by an expert gastroenterologist from Vall d'Hebron Hospital, a total of four main FGID categories were identified (see table 9). As seen in table 10, a total of 22 main organic disorders were identified.

Table 9*Main FGID Categories and Symptoms*

Category	Symptoms
Oesophageal Disorders	Reflux/ Gastroesophageal reflux
Gastroduodenal Disorders	Dyspepsia (dysmotility and mixed) Vomiting
Bowel Disorders	Abdominal distension/flatulence/meteorism Chronic diarrhoea Irritable bowel syndrome Functional constipation
Anorectal disorders	Incontinence

Table 10*Main Organic Disorders and Examples for each Subcategory*

Organic disorder	Examples for each subcategory
Anaemia	Iron-Deficiency Vitamin B ₁₂ deficiency
Bariatric surgery	Gastric by-pass Obesity
Cancer	Adenocarcinoma (Duodenum/Polyp) Cancer of the oesophagus Lung cancer MALT lymphoma Tumours (liver, gastrointestinal stromal tumour)
Cysts	Liver cyst Pancreatic cyst
Eating disorders	Anorexia nervosa

Organic disorder	Examples for each subcategory
	Bulimia nervosa
Food intolerances/ allergies	Coeliac disease Eosinophilic esophagitis Lactose intolerance
Gallbladder diseases	Cholelithiasis Choledocholithiasis Gallbladder polyp
Gastroesophageal diseases	Reflux disease Barrett's oesophagus
Genetic disorders	Hemochromatosis Pancreatic divisum
Infections	Oesophageal candidiasis Giardia lamblia Helicobacter pylori Hepatitis (hepatitis B and C; chronic hepatitis) Campylobacter coli infection Intestine parasite infection
Inflammation	Colitis Inflammatory Bowel disease: Ulcerative colitis (ulcerative proctitis); Crohn's disease Non-specific ileitis Pancreatitis (chronic and acute) Pancreatic calcification Proctitis
Intestine disorders	Bile acid malabsorption Intestinal subocclusion Duodenal ulcer
Jaundice	Hyperbilirubinemia
Liver disorders	Bile hamartomatosis Chronic autoimmune hepatitis Cirrhosis: Primary biliary cirrhosis (or cholangitis)/liver cirrhosis

Organic disorder	Examples for each subcategory
	Gilbert's syndrome Hepatic haemangioma Hepatopathy/liver disease: Alcoholic liver disease Hypertransaminasemia Liver lesions Steatohepatitis/ Steatosis: Alcohol-related fatty liver disease; non-alcoholic fatty liver disease
Lower digestive tract disorders	Adenomatous polyp Anal fissure Colonic inertia Colon polyp/colonic polyp/gastric polyp Diverticulitis Diverticulosis: Colonic diverticulosis Haematuria Haemorrhoid disease Rectorrhagia Sigmoiditis
Mental health disorders	Bipolar (manic depression) Paranoid personality disorder
Neoplasia	Gastric neoplasia Colon neoplasia Intraductal papillary mucinous neoplasm Benign tumour (pancreas)
Neurodegenerative disorders	Parkinson's disease
Oral malodours	Halitosis
Pain disorders (upper abdomen)	Epigastric pain
Stomach diseases	Abdominal migraine Dumping syndrome Duodenal polyp Gastritis: Atrophic gastritis/chronic gastritis Gastric erosion

Organic disorder	Examples for each subcategory
	Gastric polyps Gastric ulcer
Swallowing difficulties	Achalasia Dysphagia Oesophageal spasm Gastroesophageal reflux Pharyngeal foreign body Zenker's diverticulum
Miscellaneous	Chest pain Gastrointestinal bleeding Gastrectomy Leiomyoma Nausea Splenomegaly Submucosal lesions Vomiting Weight loss

4.2.2. Analyses with incongruence as a dichotomous variable.

As seen in figure 9, initially 2,261 patients were assessed in the consultation room. After identifying the patient's diagnosis, 1,562 patients met the criteria to be included in the analyses. A total of 699 patients were excluded from the original sample due to not having completed at least the physical functioning subscale of the SF-36 questionnaire. This was essential in order to be able to calculate the incongruence score. Within this sample, two patients also met criteria (a) and (b) which was related to the presence of an intellectual disability and cognitive impairment. From the 1,562 patients that were included, 1,002 were identified as congruent patients, and the remaining 560 were considered to be incongruent patients. Sociodemographic characteristics between incongruent and congruent groups were also assessed and are presented in table 11.

Figure 9

Flow diagram of incongruence as a dichotomous variable

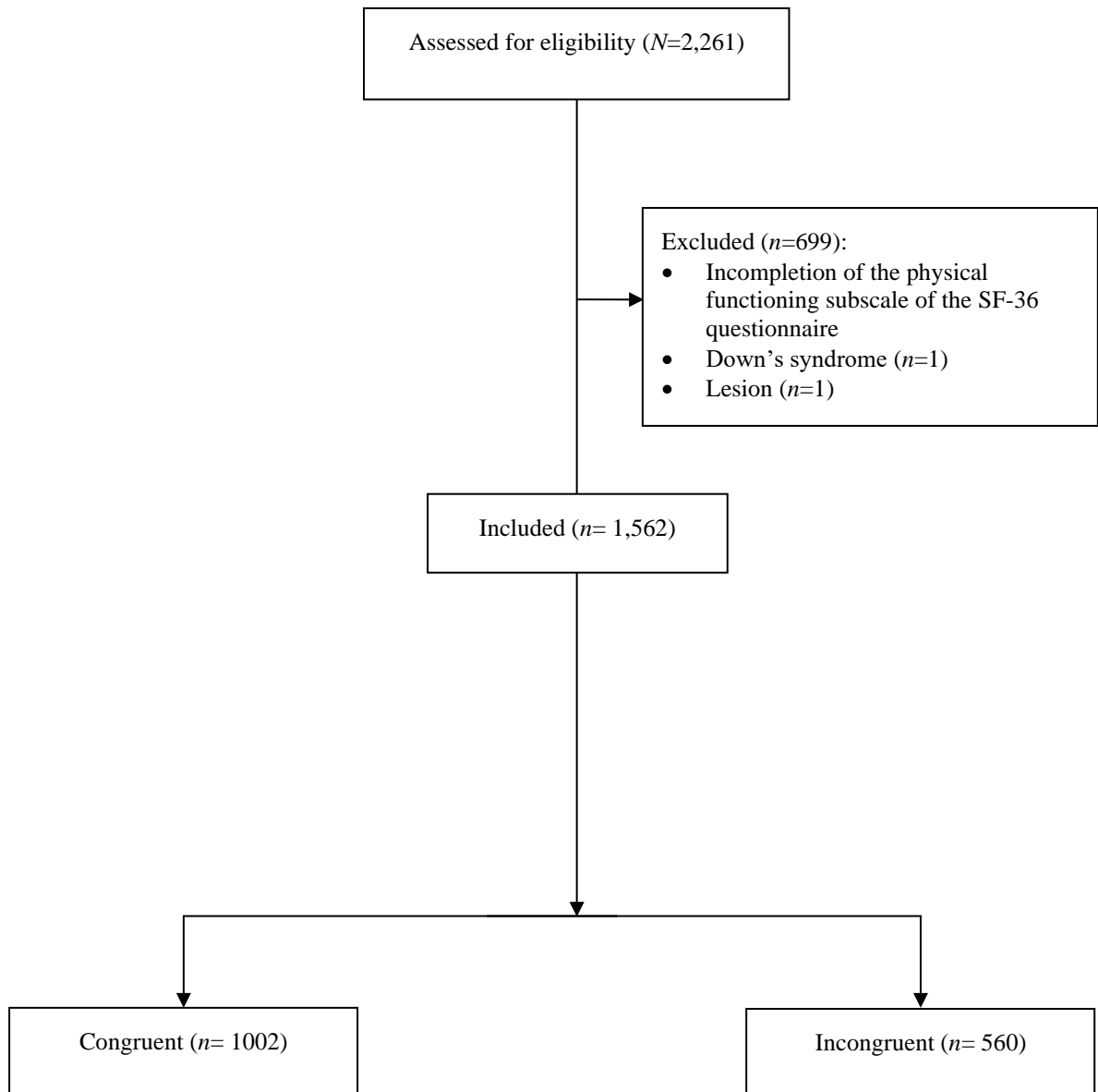


Table 11*Sociodemographic Characteristics of the Sample by Incongruence*

	Congruent (n=1002)		Incongruent (n=560)		Statistical significance	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>t</i>	<i>p</i>
Age (M ± SD)	52.22	17.257	64.86	14.819	15.225	< .001
	<i>N</i>	%	<i>N</i>	%	<i>OR, 95%</i>	<i>p</i>
Sex (% females)	595	59.4%	445	79.6%	2.664, 2.092-3.391	< .001
Education (% with a degree or higher)	220	22.0%	53	9.5%	2.698, 1.959-3.716	< .001
Marital status (% Married or stable relationship)	683	68.4%	309	55.8%	1.714, 1.383-2.123	< .001
Employment status (% employed)	483	48.3%	108	19.3%	3.901, 3.057-4.979	< .001

4.2.2.1. We expected to find differences for the variable incongruence. In other words, we anticipated that there would be statistically significant differences between patients with incongruent and congruent appraisals for all of the sociodemographic variables. We predicted that patients with incongruent appraisals with physicians would most likely be older, female, have lower levels of education, less likely to be married or in a stable relationship and be in employment than patients with congruent appraisals with physicians (H1.1).

Statistically significant differences were found between the incongruent and congruent groups for all of the sociodemographic variables. Patients in the incongruent group were older ($M= 64.86$, $SD= 14.819$) than patients in the congruent group ($M=52.22$, $SD= 17.257$) and were more likely to be female (79.6%) than male (20.4%).

Patients in the incongruent group were less likely to have a university degree or a higher educational qualification (9.5%), to be married or in a stable relationship (55.8%) and to be in employment (19.3%). Based on the odds ratio, the odds of having a university degree or a higher qualification were 2.7 times higher in the congruent group than in the incongruent group, the odds of being married or in a stable relationship were 1.7 times higher in the congruent group than in the incongruent group and the odds of being employed were 3.9 times higher in the congruent group than in the incongruent group.

4.2.2.2. *We predicted higher [overall] psychological distress scores and for each of the different subscales (e.g., somatisation, depression and anxiety) for patients with incongruent appraisals with physicians compared to those with congruent appraisals (H1.2).*

Independent samples t-tests were conducted to evaluate the effect of incongruence on levels of psychological distress. The t-tests were statistically significant for different types of psychological distress (somatisation $t(875.210) = 13.904, p < .001, d = -.808$; depression $t(866.828) = 11.896, p < .001, d = -.694$; anxiety $t(849.058) = 9.864, p < .001, d = -.580$ and overall psychological distress $t(822.439) = 13.298, p < .001, d = -.793$). An examination of the group means indicated that patients in the incongruent group on average had higher levels of psychological distress than patients in the congruent group.

4.2.2.3. *We predicted higher [overall] psychological distress scores and for each of the different subscales (e.g., somatisation, depression and anxiety) for patients with a functional gastrointestinal diagnosis compared to patients with an organic diagnosis (H1.3).*

From the current sample we found that 785 could be classified as having a functional gastrointestinal disorder and 777 patients could be considered as having an organic disorder. When comparing the psychological distress levels between the two diagnosis groups, we found statistically significant differences between psychological distress and diagnosis: somatisation $t(1554.376) = 7.379, p < .001, d = .374$; depression $t(1552) = 2.441, p < .05, d = .124$, anxiety $t(1538.284) = 4.951, p < .001, d = .251$ and overall psychological distress $t(1516.529) = 5.487, p < .001, d = .281$. Higher scores were found on all the psychological distress subscales for patients with a functional gastrointestinal diagnosis than patients with an organic diagnosis.

4.2.2.4. *We anticipated higher physician satisfaction scores for patients with congruent appraisals with physicians compared to those with incongruent appraisals. We also predicted higher physician satisfaction scores for patients with an organic diagnosis compared to patients with a functional gastrointestinal diagnosis (H1.4).*

Independent samples t-tests were applied to evaluate whether the average satisfaction score with physicians differed significantly depending on the presence of incongruence and a functional gastrointestinal diagnosis. The test was not statistically significant when comparing congruent and incongruent groups $t(1436) = -.305, p = .761, d = .017$. However, the test was statistically significant when comparing the two diagnosis groups with physician satisfaction $t(1456.755) = -1.970, p < .05, d = -.103$. Patients in the incongruent group had only slightly lower levels of satisfaction with physicians ($M = 41.84, SD = 4.25$) than the congruent group ($M = 41.91, SD = 4.21$). Patients with a functional gastrointestinal disorder had lower levels of physician satisfaction ($M = 41.69, SD = 4.37$) than patients with an organic diagnosis ($M = 42.12, SD = 4.05$).

4.2.2.5. *We expected statistically significant differences in psychological distress scores based on the type of appraisal (incongruent v congruent) that the patient had with their physician (this hypothesis attends to the first main effect). We expected statistically significant differences in psychological distress scores based on the diagnosis (functional v organic) of the patient (this hypothesis attends to the second main effect). We expected to find statistically significant differences in psychological distress scores based on the type of appraisal that the patient had with their physician and the patient's diagnosis (this hypothesis relates to the interaction effect) (H1.5).*

Table 12 presents the results of the general linear models using two independent variables: incongruence (i.e., congruent or incongruent appraisals) and diagnosis (functional or organic diagnosis) and a dependent variable (psychological distress subscales and overall psychological distress). There were statistically significant differences in psychological distress scores based on the type of appraisal (first main effect hypothesis). Statistically significant differences were also found for the psychological distress scores based on diagnosis (second main effect hypothesis). No statistically significant differences were found for psychological distress scores based on type of appraisal that the patient had with the physician and the patient's diagnosis (interaction effect hypothesis).

Table 12

General Linear Models of the BSI-18 Scores

Variables	Incongruence			Diagnosis (FGID, Organic)			Interaction		
	<i>F</i>	<i>p</i>	ηp^2	<i>F</i>	<i>p</i>	ηp^2	<i>F</i>	<i>P</i>	ηp^2
Somatisation	240.338	<.001	.135	57.776	<.001	.036	.260	.610	<.0001

Variables	Incongruence				Diagnosis (FGID, Organic)		Interaction		
Depression	170.245	<.001	.100	5.693	<.05	.004	1.338	.248	.001
Anxiety	120.520	<.001	.073	24.342	<.001	.016	.078	.780	<.0001
General Distress	221.835	<.001	.129	31.826	<.001	.021	.448	.504	<.0001

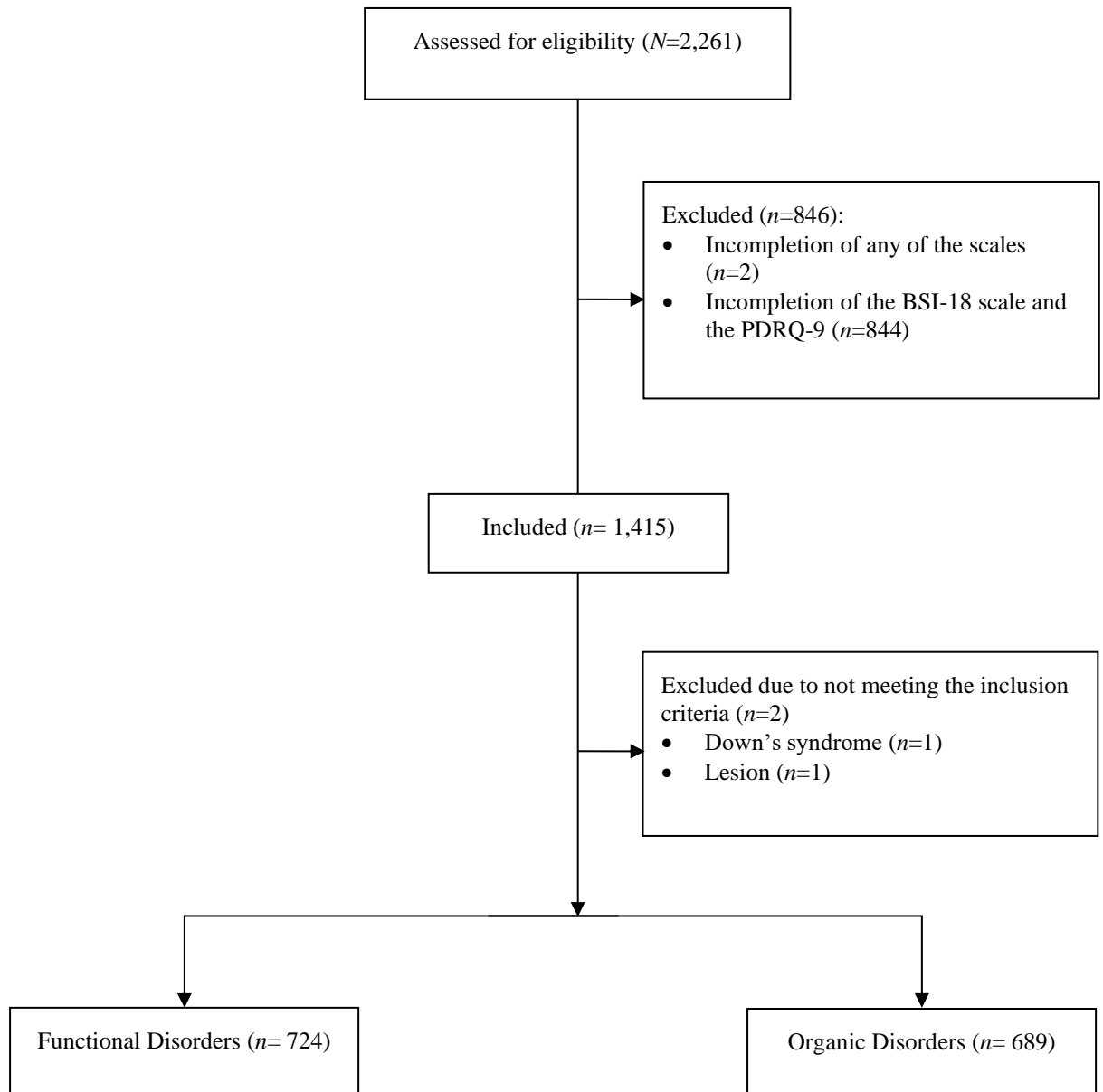
FGID: Functional Gastrointestinal Disorders

4.2.3. Analyses carried out with incongruence as a continuous variable.

Initially, a total of 2,261 patients were assessed. As seen in figure 10 a total of 1,413 met the inclusion criteria to be completed in the analyses. After establishing the patient's diagnosis, 846 were excluded for either not completing any of the measures in the study ($n=2$) or for not completing the BSI-18 measure and the PDRQ-9 measure ($n=844$). Completion of the study was measured by whether the participants had an overall score for both 'overall psychological distress' (i.e., a general distress score) and for overall PDRQ-9 (i.e., a score for overall satisfaction with their consulting physician). Some participants had one of the scores but not the other, if this was the case then they were excluded. In addition, as mentioned previously, two patients were also excluded due to the presence of an intellectual disability and cognitive impairment. From a sample of 1,413 patients, 724 patients were classified as having a functional gastrointestinal disorder and 689 met the criteria for an organic disorder.

Figure 10

Flow diagram of patients with a FGID or an organic diagnosis



4.2.3.1. *From the sociodemographic variables we expected to find a statistically significant difference between the mean age of patients who completed the study compared to those who did not complete the study. We also expected to find differences between the two groups regarding other sociodemographic variables (H2.1).*

A *t*-test was conducted to test whether the age of the patients completing the study was significantly higher than the patients not completing the study. The mean age of participants that completed the study was significantly lower ($M=56.70$, $SD=17.434$) than the participants that did not complete all the measures in the study ($M= 58.61$, $SD=19.200$); $t(1599.760) = 2.359$, $p < .05$.

The current sample had a total of 939 females (66.4%). A higher number of females completed the study (66.4%) than did not complete the study (65.5%). The percentage of males that completed the study was lower (33.6%) than those who did not complete the study (34.5%). From the patients that took part, 901 patients were married or in a stable relationship (64.1%), 252 had a university degree (17.8%), 530 were in employment (37.5%) and 1078 (76.3%) were in the follow-up group.

4.2.3.2. *We expected that incongruence scores would be positively correlated with psychological distress. We also anticipated that incongruence would be negatively correlated with the mental health component score (H2.2).*

A Pearson correlation was carried out to examine the relationship between incongruence and psychological distress. As illustrated in table 13 , statistically significant positive correlations were found between incongruence and overall psychological distress $r(1502) = .369$, $p < .001$, as well as with the individual psychological distress subscales;

somatisation $r(1538) = .371, p < .001$, depression $r(1533) = .342, p < .001$ and anxiety $r(1530) = .274, p < .001$. A statistically significant negative correlation was found between incongruence and the mental health component score $r(1546) = -.438, p < .001$. No correlation with the physical health component score was carried out as incongruence is constructed with one of its components.

Table 13

Correlations between the IV's, Psychological Distress and Physician Satisfaction

Variables	Incongruence ^a	Diagnosis ^b	Gender	Age
Distress (BSI-18)				
Somatisation	.371***	-.184***	.205***	-.083**
Depression	.342***	-.062*	.131***	.033
Anxiety	.274***	-.125***	.140***	-.085**
General Distress	.369***	-.139***	.179***	-.052*
QoL (SF-12)				
Mental Health	-.438***	.136***	-.220***	-.043
Physical Health	— ^c	.074**	-.222***	-.338***
Physician satisfaction				
PDRQ-9	-.027	.051*	.016	.115***

Note. Gender and diagnosis were calculated using a point-biserial correlation. a: incongruence was defined as the differing view between patients and physicians; b: diagnosis was defined as the presence of a functional or an organic disorder; c: The correlation of physical health with incongruence is not calculated as the former is used to calculate the latter. * $p < .05$. ** $p < .01$. *** $p < .001$.

4.2.3.3. *We expected higher incongruence scores for patients with a functional gastrointestinal diagnosis than patients with an organic diagnosis. We also predicted lower QOL for patients with a functional gastrointestinal diagnosis than patients with an organic diagnosis (H2.3).*

When conducting an independent samples t -test we found no statistically significant differences for incongruence between patients with a functional gastrointestinal diagnosis and patients with an organic diagnosis $t(1560) = -1.510, p = .13, d = -.076$. Statistically significant differences were found for QOL: mental health component score $t(1558.858) = -5.417, p$

$< .001$, $d = -.274$ and the physical component score $t(1528) = -2.907$, $p < .05$, $d = -.149$. After examining the group means, patients with a functional gastrointestinal diagnosis on average had lower scores on QOL than patients with an organic diagnosis.

4.2.3.4. *We anticipated that incongruence would be negatively correlated with physician satisfaction. (H2.4).*

No statistically significant correlations were found between incongruence and physician satisfaction $r(1438) = -.027$, $p = .308$.

4.2.3.5. *We expected that female patients would have higher incongruence scores, [overall] psychological distress, as well as for each of the different psychological distress subscales than male patients. We expected that female patients would have lower quality of life than male patients. We also explored whether female patients would have lower physician satisfaction than male patients. We expected that age would be positively correlated with incongruence, [overall] psychological distress, its subscales and physician satisfaction. We predicted that age would be negatively correlated with QOL (H2.5).*

From the independent samples t -test statistically significant differences were found between males and females for incongruence $t(1194.272) = -8.749$, $p < .001$, $d = -.446$; overall psychological distress $t(1181.625) = -7.503$, $p < .001$, $d = -.385$ and the subscales: somatisation $t(1229.159) = -8.838$, $p < .001$, $d = -.445$; depression $t(1180.919) = -5.514$, $p < .001$, $d = -.282$ and anxiety $t(1210.854) = -5.910$, $p < .001$, $d = -.300$. An examination of the group means indicated that females on average had higher levels of psychological distress (as well as for each of the different subtypes) than males. Statistically significant differences were found

between males and females for QOL: mental health component score $t(1576) = 8.945, p < .001, d = .479$ and the physical health component score $t(1075.434) = 9.099, p < .001, d = .483$. From the group means female patients on average had lower scores on the QOL subscales than male patients. No statistically significant differences were found between male and female patients for physician satisfaction $t(1458) = -.627, p = .531, d = -.035$.

The results displayed in table 13 show a positive statistically significant correlation between age and incongruence $r(1562) = .377, p < .001$. A statistically significant negative correlation was found for general psychological distress $r(1533) = -.052, p < .05$. A statistically significant negative correlation was found for somatisation $r(1570) = -.083, p < .01$, as well as for anxiety $r(1564) = -.085, p < .01$. No statistically significant relationship was found for depression $r(1565) = .033, p = .187$. The results in table 13 show that age is statistically significantly negatively correlated with the physical health component score $r(1541) = -.388, p < .001$. No statistical significance was found between age and the mental health component score $r(1580) = -.043, p = .088$. Age was statistically significantly positively correlated with physician satisfaction $r(1462) = .115, p < .001$.

4.2.3.6. *We predicted that the variables incongruence, age, gender, physician satisfaction and diagnosis would significantly predict [overall] psychological distress (H2.6).*

A multiple regression model was carried out to investigate whether incongruence, age, gender, physician satisfaction and diagnosis could significantly predict psychological distress. Table 14 demonstrates a model with all the aforementioned variables which explained 20.4% of the variance $F(5, 1387) = 72.402, p < .001$. All the variables were statistically significant predictors of psychological distress. It was found that gender significantly predicted psychological distress ($\beta = .099, p < .001$), as did incongruence ($\beta = .414, p < .001$).

Table 14*Multiple Regression Analysis for Variables Predicting Psychological Distress*

Variables	B	SE B	β	<i>t</i>	<i>p</i>
Incongruence ^a	.207	.013	.414	15.661	<.0001
Physician satisfaction	-.296	.076	-.094	-3.879	<.0001
Age	-.137	.020	-.180	-6.808	<.0001
Gender	2.774	.698	.099	3.975	<.0001
Diagnosis ^b	-2.894	.655	-.109	-4.417	<.0001

Note. Adjusted R^2 = .204, a: incongruence was defined as the differing view between patients and physicians; b: diagnosis was defined as the presence of a functional or an organic disorder.

4.2.3.7. *We anticipated that physician satisfaction, age, gender and diagnosis would significantly moderate the relationship between incongruence and [overall] psychological distress (H2.7).*

Moderation models were carried out for physician satisfaction, age, gender, and diagnosis as moderators for incongruence and psychological distress.

The model incongruence and physician satisfaction with the consultation explained 14.6% of the variance. The two predictors were found to be statistically significant predictors of overall psychological distress $F(3, 1390) = 80.136, p < .001$. Incongruence ($\beta = .452, p < .05$) and satisfaction with the consultation ($\beta = -.115, p < .001$) contributed to the model. The interaction between satisfaction with the consultation and incongruence did not predict overall psychological distress ($\beta = -.091, p = .698$).

The model incongruence and age explained 19.2% of the variance $F(3, 1498) = 118.888, p < .001$. Incongruence contributed significantly to the model ($\beta = .904, p < .001$). Age also contributed to the model ($\beta = -.148, p < .001$), as well as the interaction between age and incongruence ($\beta = -.499, p < .001$).

The results from the regression model indicate that incongruence and gender explain 14.9% of the variance. The model was a significant predictor of overall psychological distress $F(3, 1497) = 87.637, p < .001$. While incongruence ($\beta = .369, p < .001$) and gender ($\beta = .114, p < .001$) contributed significantly to the model, the interaction between incongruence and gender was not found to be statistically significant ($\beta = -.022, p = .828$).

The model incongruence and diagnosis explained 16.1% of the variance and the model was a significant predictor of overall psychological distress $F(3, 1498) = 96.134, p < .001$. Incongruence contributed more to the model ($\beta = .321, p < .001$) than diagnosis ($\beta = -.170, p < .001$). The interaction between incongruence and diagnosis was not found to be statistically significant ($\beta = .058, p = .450$).

As seen in table 15 a significant interaction was found only for age ($\beta = -.499, t = -5.008, p < .001$).

Table 15

Moderator Models Examining the Effect of Variables on Incongruence and Psychological Distress

Models	Adjusted R^2	Incongruence × moderator interaction	B	t	p
1	.146	Physician satisfaction	-.091	-.388	.698
2	.191	Age	-.499	-5.008	<.001
3	.148	Gender	-.022	-.217	.828
4	.160	Diagnosis	.058	.756	.450

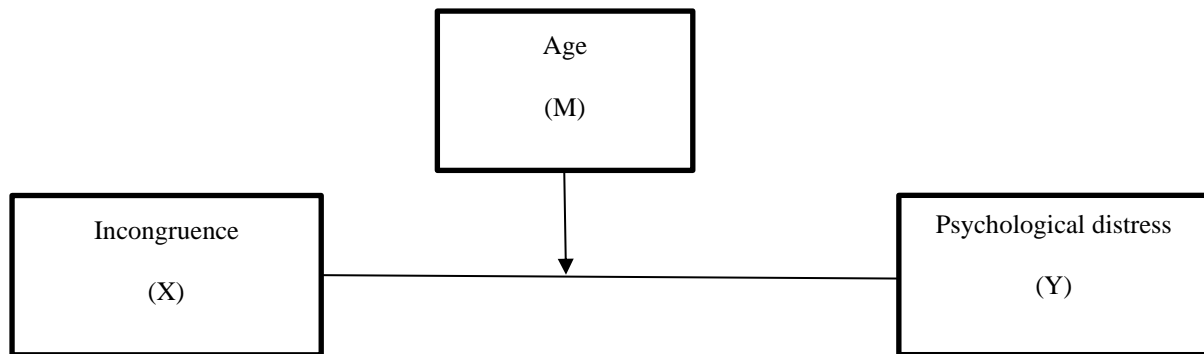
Note. IV: incongruence in all models, DV: Psychological distress in all models, incongruence was defined as the differing view between patients and physicians; diagnosis was defined as the presence of a functional or an organic disorder.

4.2.3.8. Exploring the moderation effect of age on incongruence and psychological distress.

The results found that age was the only variable to statistically significantly predict the relationship between incongruence (independent variable) and psychological distress (dependent variable). Figure 11 illustrates the relationship between the aforementioned variables.

Figure 11

An explanation of the relationship between incongruence, psychological distress and the moderator (age).



The variable ‘age’ was dichotomised based on the mean age ($M=57.39$, $SD= 18.12$) of the sample. A total of 1,072 patients were in the ‘young’ group which was coded as ‘1’ (<57.39 years of age) and 1,173 were in the ‘older’ group coded as ‘2’ (≥ 57.39).

Pearson correlations were carried out stratifying age by the ‘young’ and ‘older’ groups. For the ‘young’ group there was a statistically significant positive correlation between incongruence and psychological distress $r(743) = .478$, $p < .01$. For the ‘older’ group a statistically significant positive correlation was also found between incongruence and psychological distress $r(759) = .369$, $p < .01$.

From the main moderation analysis as demonstrated in table 16 we see that there is a significant interaction effect for moderation, $b = -.004$, 95% CI $[-.005, -.002]$, $t = -5.01$, $p < .01$, suggesting that the relationship between incongruence and psychological distress is moderated by age.

Table 16

Moderation Analysis of the Variables Psychological Distress, Incongruence and Age

	<i>b</i>	SE B	<i>t</i>	<i>p</i>
Constant	15.70	.334	47.01	<.001

Incongruence	.247	.013	18.72	<.001
Age	-.183	.019	-9.50	<.001
Interaction	-.004	.001	-5.01	<.001

Note. $R^2 = .19$

4.2.4. Qualitative analysis.

4.2.4.1. Patient Interviews Transcription Analysis.

Three main patient themes were found using patient interview transcription analysis (i) Illness, emotional and personal problems (ii) Disease-health system interaction and (iii) Health system. As seen in table 17, this yielded a total of 33 subcategories.

Table 17

The Proportion of Patient Subcategories

	<i>N</i>	%
Illness, Emotional and Personal Problems		
Physical illness-emotional problems	14	7.14%
Acceptance of symptoms	13	6.63%
Emotional-consequences	25	12.76%
Relationship-consequences	18	9.18%
Consequences-daily life	49	25%
Stomach upset-stressful events	31	15.82%
Emotional/personal problems	24	12.24%
Experience of the disease	22	11.22%
Disease-Healthcare System Interaction		
Empathy towards professionals	13	6.67%
Uncertainty over waiting times	30	15.38%
Dissatisfaction with professionals	18	9.23%
Dissatisfaction with treatment	3	1.54%
Discomfort-absence of diagnosis	10	5.13%
Need patient strategies	7	3.59%
Satisfaction with professionals	49	25.13%
Feelings of isolation/abandonment	19	9.74%
The feeling of being understood	22	11.28%
Feeling misunderstood	17	8.72%
Veracity of complaints	7	3.59%
Health System		

	<i>N</i>	%
Comprehensive care	8	5%
Lack of clarity	7	4.38%
Consultation time	9	5.63%
Generational change	11	6.88%
Communication with professionals	19	11.88%
Coordination between services	9	5.63%
Difficulty accessing specialists	15	9.38%
Not listened to enough	10	6.25%
Lack of resources	17	10.63%
Inaccessibility of the professional	4	2.50%
Waiting lists	26	16.25%
Health insurance	12	7.50%
Participation in studies	6	3.75%
Possible negligence	7	4.38%

4.2.5. Main Patient Theme One: Illness, Emotional and Personal Problems.

The first main patient theme refers to the patient's state of health both physically and mentally. It also refers to the consequences derived from the digestive disorder, the place that it occupies in the life of the patient and the relationship between physical discomfort and emotional problems. As presented in table 17, this led to a total of eight subcategories (see page 200 for a description of all of the patient codes for theme one).

4.2.5.1. *Consequences in daily life.*

Patients were asked to describe the way in which their symptoms, such as pain, had affected their daily life. Fragments of narrative were included in this subtheme if it referred to the way in which the digestive disorder had influenced the patient's everyday activities. The largest number of patients in the sample belonged to this category. Patients mentioned the effect that symptoms had on their eating habits, sleeping patterns, physical abilities and employment status (R2.2).

The most common area that patients referred to in the focus groups were eating habits. Patients mentioned the need to adapt their routines as a coping mechanism for their symptoms. For example, some strategies that were used by patients were eating before a certain time,

restricting the consumption of certain food groups, not eating outside of the house and ordering meals that they had already tried.

Patients spoke of the effect that symptoms have had on their quality of sleep “At night I sleep very badly, from the pain and everything...I am used to it” (Patient 7, female, focus group two). Other patients spoke of having to change their sleep patterns in order to reduce the likelihood that the symptoms get worse, for instance one patient stated that due to her fatigue that she had to be in bed by a certain time in order to ensure that she was not bedridden and unable to move the following day.

Additionally, patients spoke of the link between symptoms and a deterioration in physical health “I felt... before, I had very good health, but, for half a year, I have felt that I have less strength” (Patient 3, male, focus group three). Other patients spoke of the pain as being debilitating with one patient describing the experience as “unbearable” and being “unable to endure the pain”. Patients spoke of the knock-on effect of a worsening physical health on their mental health with some suffering from depression, and consequently leading to an inability to work.

4.2.5.2. *Relationship consequences.*

The narratives refer to the effect of the digestive disorder on personal relationships and how the person relates to others. Many patients outlined that their symptoms had led to changes in their interactions with partners, family and friends. Patients indicated that their relationships were more strained (R2.2) “I would speak to him more forcefully [her husband] than normal, as a result he would get angry” (Patient 7, female, focus group 2). Whilst certain patients were able to confide in their inner circle regarding their symptoms, the majority of patients had difficulties with maintaining relationships (R2.2). For instance, some experienced worse relationships due to their lack of interest in socialising “I did not want to talk and meet my

friends, maintain relations with my parents...” Patient 3, male, focus group three), frequent cancellations and worries around food “...they invite you to a party, [and] I am already thinking, I am not going to be able to eat” (Patient 3, female, focus group eight).

Some patients found their changing relationships as very challenging, thus experiencing lower mental health (R2.2). Others indicated that they felt pressure to follow societal norms, which often left to them not wanting to partake in social events.

And then the other problem of eating so little has affected my social relationships, in the sense that I do not attend meals, because while everyone eats a normal amount I have to eat two tablespoons, I feel bad and I feel really uncomfortable.

(Patient 2, female, focus group 6)

4.2.5.3. *Physical illness-emotional problems.*

This subtheme refers to narratives in which a physical illness is linked to mental health problems. A close relationship was found between a deterioration of physical health and the presence of a mental health disorder. The most commonly discussed was the presence of depression (R2.2) “...You have a disease and that is why you are depressed” (Patient 1, male, focus group two) which was reiterated throughout the focus group discussions “It is because of a depressed state [that] I am not happy” (Patient 3, male, focus group three). Other patients mentioned feeling “overwhelmed”, “stressed”, “insecure” and having “lower self-esteem” (R2.2). Patients also experienced comorbidities both emotionally and physically, which inevitably had their overall wellbeing “I continue with these pains...there are times when I am very stressed or do not sleep because I have problems with depression...” (Patient 3, female, focus group 8). Some patients referred to difficulties in managing their symptoms due to societal pressures and stigma.

What happens is you start to feel insecure...I already had Vitiligo [it] suddenly appeared when I was 20 years old...like it lowers your self-esteem a bit too...and then with the stomach [problems], then apart from my back I have to have an operation for my hernias and protrusion.

(Patient 4, female, focus group seven)

4.2.5.4. Acceptance of symptoms.

The narrative refers to the acceptance of symptoms, the incorporation of these into their daily life or the need to adapt their lifestyle as a result of the symptoms. For example, many patients mentioned that they have had to learn to live with their symptoms and become more accustomed to them (R2.2). Patients appeared to find their own strategies of accepting the disease “It does not affect me, I mentalise it...one mentalises the pain” (Patient 4, female, focus group 2). Another patient spoke of acknowledging that their lifestyle would not be the same as before, and thus found that adapting to the disease was essential in the acceptance process “... I like everything, I have no problem with food, but I know which [foods] are good for me and which ones are not, and that is what I am doing. I am happy” (Patient 6, female, focus group 4).

Other patients spoke of becoming more accustomed to living with the disease and finding that over time it became easier to cope with the symptoms “You get used to living with it... I do not know, you get used to it, you have no choice” (Patient 3, female, focus group 7). Another patient reiterated this by stating that she has learnt to get past the pain due to becoming more used to it “Well, mine does not affect me... [I have] a normal life. Yes, it is true that in relation to the pain I get through it ... because I have gotten used to it” (Patient 2, female, focus group 7).

4.2.5.5. *Experience of the disease.*

These fragments of text refer to how each individual lives with their disease or symptoms depending on how they interpret them, allowing it or not to affect them, or occupying a central place in their life. For example, some patients recognise that the way in which they view their disease will be different from other patients. Additionally, that this is a continually evolving learning process that may be dependent on the moment that the patient is in. One patient spoke of the disease experience as being unique and that her experience has changed over time “But there is a process... maybe if you had done this talk two years ago I would be here crying” (Patient 4, female, focus group 4). Similarly, the way in which the patient views the disease can also be dependent on their resources and the type of support that they have available “I have learned a lot, that by learning, we have to learn to control ourselves mentally and go to someone who can teach us, because I guarantee it, it improves a lot” (Patient 2, female, focus group 8).

Patients spoke of using positivity and a proactive approach in order to cope better with their symptoms. For instance, one patient decided that regardless of her past that she would not allow the disease to consume her “I have had several operations, but I am very well, I take it that way, and I feel good” (Patient 8, female, focus group four). Some patients spoke of the need to be determined “Come on, it is a new day, lets move forward” (Patient 1, female, focus group six) and not only rely on external factors to help them progress forward “The medication will help you, but if you do not use willpower, you are not going anywhere” (Patient 5, male, focus group five). Additionally, one patient spoke of the importance of taking control of their illness and taking an active approach towards the consultations and physicians “I have been adapting, because although we are patients here, I believe that it is a word that does not have to make us passive in front of the service, in this case in front of the doctor” (Patient 2, female, focus group six).

On the other hand, some patients spoke of their difficulties, with some of these being due to a possible lack of continual contact (R2.1) and feeling that due to the health system that they are not being prioritised.

I would say that I feel alone I do not have the answer, well, I would need that this...one of the things about fibromyalgia is that it is a bit like Alzheimer's, we are losing ourselves through life...we do not know where we are going, what we have to do ...I am lost within the system.

(Patient 4, female, focus group five)

4.2.6. Main Patient Theme Two: Disease-Healthcare System Interaction.

The second main patient theme ‘disease-health system interaction’ includes codes that result from the interaction that takes place between patients, professionals that work in healthcare and the healthcare system itself. This theme includes the opinions and experiences that patients have with the global health system, the relationship they have with physicians, how these aspects affect their diagnostic search and consequently their healing process. As presented in table 17, this led to a total of eleven subcategories with the most predominant category being ‘satisfaction with professionals’ (see page 202 for a full list of the patient codes for theme two).

4.2.6.1. *Satisfaction with professionals.*

Parts of the narrative that refer to satisfaction with the treatment and the quality of health care that they have received that they have received as a whole. Most patients were satisfied with their physician and the high quality of healthcare they were receiving (R2.1).

Patients used positive language to describe their consulting physician “With the magnificent doctor” (Patient 1, male, focus group one) which was repeated across the focus groups and between different patients “Scientifically correct or not, that I do not know, [but]

as a person he looked after us very well (Patient 5, male, focus group two). Additionally, the language used suggests that the physicians show an empathetic “I have no complaints, she is an excellent doctor, she shows a lot of concern” (Patient 4, female, focus group three) and caring approach “I think that they [doctors and service in general] really listen to you” (Patient 4, female, focus group five).

Patients also indicated that in general they thought very highly of physicians and that they have a strong rapport and alliance (R2.1) with their physician “[She is] very nice to me...we get along very well” (Patient 1, female, focus group five). This also appears to be the case across different specialities “There is a cardiologist here, that [is] wonderful, everyone says it” (Patient 4, female, focus group one) and across different multidisciplinary teams “I see [physicians] for my heart, my stomach, and rheumatism...all three are wonderful” (Patient 5, male, focus group five).

Whilst many patients did not refer to psychological assistance, certain patients mentioned that they were very satisfied with professionals and that at times they also took on the role of the psychologist. For example, one patient spoke of the support she received from a psychiatrist (R2.2) “...and the psychiatrist was very good, she also takes care of you.... very well... [she is] exceptional, apart from being a psychiatrist, she was [acting as] a psychologist” (Patient 1, male, focus group one).

4.2.6.2. *The feeling of being understood.*

This category refers to the extent that patients feel that health professionals strive to understand their discomfort and their situation. Similarly to previous themes, this theme presents a positive description of the consulting physician as being sympathetic and a good listener (R2.1) “Yes, she is very nice, because she listens to you, she listens to the patient” (Patient 7, male, focus group five). Many of the patients spoke of the physician’s determination

to assist them “I have seen that they tried to help me find a problem” (Patient 3, male, focus group three), as well as the motivation to find a solution “She has repeated all the tests on me using high definition [equipment]...she has always done a more complete one” (Patient 3, female, focus group six). Patients mentioned that regardless of the fact that services are overcrowded, that the consulting physician will always make the time to provide good quality healthcare and meet the patient’s needs (R2.1).

...She is a doctor who listens to you, advises you... when you have a problem, [even] if she has a queue of 20 [people], until she finishes with you, she does not call the last one...

(Patient 7, male, focus group four)

4.2.6.3. *Uncertainty over waiting times.*

This subcategory refers to the delay in medical results and the emotional effects of waiting to consult a physician. Many patients spoke of being “anxious” and feeling “discomfort” and “distress” at not being informed on how long they would have to wait to seek help. Across the discussions, many patients described the system as being “very slow” and that they often had to endure long gaps to be seen (R2.1) “They have now given me the results from the mammogram, I did it about 4 months ago...” (Patient 4, female, focus group one). This led to some uncertainty regarding the best course of action, as well as the extent to which progress is being made.

It is still a problem because they sometimes load you up with medications and now I have to endure a year without knowing if it is good to continue [taking] so much or if it should be less...and there you are, waiting, are you doing better...are you doing worse.

(Patient 5, male, focus group 6)

Additionally, patients also spoke of their insecurities regarding the nature of their diagnosis “You are waiting for a cure, but at the same time thinking [what] if it is a chronic [condition]” (Patient 3, female, focus group six).

Patients also spoke of the frequent testing they have had to endure “I have done a lot of tests, blood tests, everything...” (Patient 3, male, focus group three) and repeatedly having the same tests done “They did all the tests, then the doctor repeated them” (Patient 3, female, focus group seven) or without notice having a different test administered “...they will do another colonoscopy and endoscopy or not, [maybe] in January it will be a stool test” (Patient 4, female, focus group one).

Although patients mentioned that they experienced some relief, many continued with the same symptoms “I still have an upset stomach, I still have them, they are not the same, not as serious” (Patient 4, female, focus group one). On the other hand, some patients spoke of being affected emotionally due the number of symptoms they have to manage and the evolution of the symptoms (R2.2).

It affects you a lot...you are aware that you have one thing and then you find out that you have something else... I have many pathologies and you cannot attend to everything and that creates a ... I do not know how to say it...disappointment...

(Patient 7, male, focus group 5)

4.2.7. Main Patient Theme Three: Health System.

The final patient theme was ‘health system’ which refers to the patient’s opinions regarding the functioning of the health system, the physician’s attitudes towards patients and the way that physicians relate to them. As illustrated in table 17 a total of fourteen codes were extracted from this theme (see page 204 for a definition of the patient codes for theme three).

4.2.7.1. *Waiting lists.*

This subcategory includes fragments of narrative that refer to the time period between requesting an appointment and being able to have a consultation with the physician. Some patients described the system as being “chaotic” at the organisational level and many used words such as “lengthy” and “excessive” when describing the waiting process (R2.1). This appeared to be mirrored across specialities.

What I see wrong are the waiting lists, because I had a CT scan in February and only now have they given me the results, they gave them to me in November, it was a CT scan, the pulmonologist was in charge of it. I mean, I am not well but they give me the results in November, [and I have been waiting] since February, so I sent a written complaint...

(Patient 8, female, focus group four)

Patients also stated that the long waiting lists also influenced communication between different professionals and that consequently this had an effect on the progress of the patient, with for instance medication changes being delayed.

A whole year waiting, [in the end] my GP said, well, this cannot continue, we are going to withdraw the Levogastrol medication because it is having a bad [effect] on other things, well of course, this information should have been given to me by my digestive doctor.

(Patient 5, male, focus group six)

Patients stated that more contact with physicians was needed (R2.1) and that having an appointment once a year was insufficient “These annual visits, depending on how you are, should be more frequent” (Patient 5, male, focus group 6) in correctly monitoring their progress. Also, there appears to be confusion as to why the health system has deteriorated over

time “Before you went to the GP and you could get an appointment for the same week, now [you have to wait] for two months” (Patient 5, male, focus group five) which was reiterated across the groups “It takes three weeks for you to have a visit with the GP... before it was two days, one day?” (Patient 6, female, focus group eight).

4.2.7.2. *Lacking in resources.*

Following on from the previous paragraph, this subtheme refers to fragments of text which make reference to the patient’s worsening impression of public health due to a lack of economic resources.

Many patients stated that the problem lies within the structure of the health system “The problem is in the organization, the problem is economical” (Patient 4, female, focus group three) and that the lack of resources invested into healthcare were likely due to the economic crisis which has consequently led to a lower quality healthcare system.

Everything is due to the cuts, we had the best health system in the world, I am talking about 10, 15 years ago, statistically it was, worldwide the first or the second, and now what are we? In the thirty-something position? Based on the statistics, they had to make cuts and where were these cuts made? Teaching and health, which is precisely where the cuts should not have been made, neither in teaching nor in health.

(Patient 3, female, focus group one)

Other patients recognised that whilst resources were limited, that the service they received was of a good standard (R2.1) “In general it is good, they cannot do more” (Patient 7, male, focus group five) and many acknowledged that the medical staff work hard to keep the system running “They do everything, the doctors. I have been in the hospital where I had my heart surgery this past year and I have seen it, but... the system is very bad” (Patient 6, female, focus group five).

4.2.7.3. *Communication with professionals.*

Fragments from this subcategory refer to the fact that adequate communication with the healthcare professional facilitates understanding. Additionally, this refers to the diagnostic process and the search for treatment, which can put patients at ease.

Some patients stated that physicians took an interest in psychosocial aspects of their life “Then the doctor asked me my age, mostly about my job, the type of life that I led, well, the type of life that I lead...” (Patient 4, female, focus group four). Many patients stated that physicians provided them with emotional support “How has Dr X helped me? Through medication, through dietary guidelines and above all, emotionally, a lot” and a warm communication style helped them to feel more valued (R2.1).

I have had this physician all my life, and he is a doctor who listens, I have never felt ignored. I have been tested, he has done blood tests, the first time he sent me to have a colonoscopy...he told me about irritable bowel [syndrome].

(Patient 3, female, focus group seven)

Many patients spoke of the importance of receiving honest communication through the use of ‘patient education’ and adequate guidelines “If the subject is important enough that you have to speak to her...she will make recommendations, advise you...” (Patient 7, male, focus group four) which helped to reassure them (R2.1).

I received information, explanations, why I have this or, why I have other things...So you go away with all of that and it seems unbelievable that it could contribute to making you feel like you are no longer alone. Also, I believe that it is because you have information.

(Patient 2, female, focus group six)

Furthermore, this was key in their ability to effectively manage their symptoms “He has helped me learn how to control myself” (Patient 2, female, focus group eight) and allowed them to better understand their treatment “They explained to me about Omeprazole, the role it played and that it could not be taken over a long period of time... receiving information gives peace of mind” (Patient 2, female, focus group six).

In contrast, other patients placed greater importance on the active role that they have in their progress. For instance, one patient stated that patients needed to use clearer language and be more direct with the physician, which would allow the physician to better support them “Sometimes we say things in a way that is not very clear...so, I think you have to say, this is what is happening to me, I have problems in the intestine, I have emotional problems” (Patient 4, female, focus group three). Additionally, patients stated that at times more assertiveness was required “Listen... I am explaining what is happening to me, [and] you are not giving it importance” (Patient 4, female, focus group three) and that greater ownership of their disorder is needed “One hopes that the professional will be the one to help us. I do not ... we have to do it ourselves” (Patient 2, female, focus group eight).

4.2.8. Physician Interviews Transcription Analysis.

There were three main physician themes (i) Intervention (ii) Patients and (iii) Health system. This yielded 28 subcategories, table 18 demonstrates the frequency of occurrence of each category.

Table 18

The Proportion of Physician Subcategories

	<i>N</i>	%
Intervention		
Openness with the patient	8	7.62%
Understanding	9	8.57%

	<i>N</i>	%
Differences in explanation	8	7.62%
Difficulty with the diagnosis	3	2.86%
Difficulties with the doctor-patient relationship	5	4.76%
Empower	5	4.76%
Lack of tools	11	10.48%
Medical record	4	3.81%
Importance of the diagnosis	7	6.67%
The importance of a relationship	12	11.43%
Comprehensive intervention	17	16.19%
The need for more time with patients with FGIDs	12	11.43%
Reassurance	4	3.81%
Patients		
Adherence to treatment	14	15.73%
Differentiating characteristics	10	11.24%
Disease awareness	11	12.36%
Mistrust	3	3.37%
Gender difference	3	3.37%
Brain-gut axis	6	6.74%
Importance of psychological aspects	20	22.47%
Importance of sociodemographic characteristics	10	11.24%
Non-acceptance of diagnosis	10	11.24%
Personality pattern	2	2.25%
Health system		
Lack of mental health referral resources	8	25%
GP	2	6.25%
Biomedical models-chronic disease	7	21.88%
The need of a psychologist	5	15.63%
Overload-consequences	10	31.25%

4.2.9. Main Physician Theme One: Intervention.

Within this theme, the codes refer to the aspects and characteristics that are most relevant when working with patients with gastrointestinal disorders. A total of thirteen subcategories were extracted from this theme (see page 206 for a full list of the codes that belonged to physician theme one).

4.2.9.1. Comprehensive Intervention.

This reflects the need and importance of providing treatment to patients that integrates physical, psychological and personal aspects. Based on the physician interviews, there are still difficulties in providing patients with an integrative approach

There are diseases, such as inflammatory disease, which are more serious than functional diseases and yet, the general impression that I have, is that the doctor who treats such patients gives little importance to the psychopathology [behind the disease] and gives more importance to the organicity of the disease.

(Physician 2, male, interview two)

There still appears to not be enough importance placed on the emotional wellbeing of the patient (R2.3) “Yes, it is normal for him to be depressed, but we are going to treat only the organic issue... the psychological issue we are going to leave it aside, why?” (Physician 2, male, interview two).

Additionally, this is made more challenging as often patients are reluctant to take part in psychological interventions and therefore physicians face challenges when recommending psychological services to patients “Patient’s do not want this either because it would require talking, opening up...that is very difficult” (Physician 3, female, interview three). Instead, patients appear to rely on pharmaceuticals “Most people want a pill that will solve the problem quickly” (Physician 3, female, interview three) and to have a ‘quick fix’, “What they want is a biomedical model, give me something and heal me” (Physician 4, female, interview four).

Some solutions were given by physicians to overcome this, such as addressing multiple factors and implementing aspects of the biopsychosocial model (R2.3) which would be particularly useful for patients with a functional gastrointestinal diagnosis.

From when they modify their diet, that you are going to give them a pharmaceutical drug, you go in depth about issue of anxiety, how they [normally] manage their problems or if they have problems then they should talk and get it off their chests...

(Physician 3, female, interview three)

However, although this approach would be beneficial, physicians are also aware of their own limitations “It is difficult sometimes because the therapy we have is limited...some of them work very well, but there are others that do not” (Physician 3, female, interview three) which have an effect on the number of services that are available “There are no resources. We do not have a psychologist” (Physician 4, female, interview four). Consequently, some physicians are also unaware of how to detect depression and anxiety, therefore effective training is still needed “The physician specialising in digestion should have a lot more training... and also the resources...to be able to access, send the patient to this type of care, because many people do not do this” (Physician 2, male, interview two).

Some physicians also acknowledge discrepancies between different healthcare systems, such as the way in which patients are managed between outpatient and hospital care. One physician stated that the pathology of the patient is more commonly treated in outpatient care but that there are still many difficulties in effectively assessing patient’s emotional wellbeing. Greater communication between professionals also needs to be encouraged, as well as multidisciplinary interventions (R2.3) which would help to provide a more holistic view of the patient’s disorder “This would go to the GP, what I understand is that joint treatment is important... I think it would greatly improve the performance of the treatments, the handling, everything” (Physician 2, male, interview two).

4.2.9.2. *Good relationship with patients.*

This indicated that a good relationship between the physician and the patient based on trust is especially important in the intervention process for patients, in particular for patients with functional digestive disorders.

A good relationship was stated as forming the foundation of any consultation regardless of diagnosis “The pillar of the management of these patients is the physician-

patient relationship” (Physician 4, female, interview four). This is especially important when trying to build trust with the patient, helping them achieve diagnostic acceptance and when transmitting messages regarding the chronicity of the disorder. Physicians outlined that it can be complicated to develop a good relationship with certain patients due to factors outside of their control such as long gaps between visits.

Due to the nature of functional gastrointestinal disorders the relationship with this subgroup of patients is different “It is different, with functional patients, yes you need to have more visits in order to have a positive effect” (Physician 3, female, interview three). Some physicians indicated that this is due to the characteristics of these patients, for instance this subgroup of patients are less likely to accept their diagnosis. Therefore, the lack of frequent contact with patients can be detrimental in the development of a strong relationship between the patient and the physician.

You have to work on empathy in each consultation, but of course, if I get somewhere and then I do not see them for almost 4 or 5 months, well, then you are going to lose it.

(Physician 3, female, interview three)

4.2.9.3. *The need for more time with functional gastrointestinal patients.*

Mirroring the previous theme, this subcategory includes narratives that refer to the need for professionals to devote more time to patients with functional digestive disorders, as well as the importance of giving them a good explanation of their pathology and creating a good physician-patient bond (R2.3).

One physician stated that it takes more time to gain the patient’s trust when they have a functional disorder, therefore physicians need to approach this subgroup of patients differently “As for functional pathologies...you have to make greater effort to involve the patient” (Physician 2, male, interview two) which often leads to greater collaboration and

commitment to change. This did not seem to be the case for organic pathologies, with many physicians indicating that they found it less challenging and easier to build a relationship with this subgroup of patients as the diagnosis was often more straight forward “When it is an organic disorder it is easier, you explain the disease to them, they understand it, they see it as something logical, very tangible, and so you gain their trust in less time” (Physician 1, female, interview one).

Other physicians spoke of requiring more time with functional gastrointestinal patients in order to explain the origin of their disease, find possible solutions and introduce the chronic disease model (R2.3). In contrast, other physicians stated that rather than providing them with more time that they required a system which would allow them to have more contact with the patient “If I am right, it does not work seeing a functional patient every six months” (Physician 4, female, interview four). This continuity of contact would thus encourage the patient to develop trust and acceptance of their diagnosis.

4.2.10. Main Physician Theme Two: Patients.

The second main physician theme refers to the characteristics and attitudes of the patients, which according to the professionals interviewed, has great relevance in the diagnostic and intervention process. A total of ten codes were extracted from this theme (see page 209 for a full list of the codes that were included in physician theme two).

4.2.10.1. *The importance of psychological aspects.*

In this subcategory we have clustered narratives that refer to the influence of emotional distress (e.g., stress, anxiety, depression, personal situations) and the effect this has on digestive problems.

One physician outlined the importance of understanding the effect of emotional factors on patients with different gastrointestinal diagnoses. Many patients are affected by multiple factors such as adverse life events “The vast majority have very severe family backgrounds...abusive parents, an abusive partner (Physician 3, female, interview three) which can lead to varying degrees of somatisation “Depending on what they have said, I say, it does not surprise me that your stomach hurts” (Physician 3, female, interview three). Additionally, physicians have indicated that these disorders affect the patient’s mood, and that they often suffer from anxiety and depression. “They refer [patients] to me...who they think they have more environmental problems or... a lot of anxiety, or that start crying...” (Physician 4, female, interview four).

One physician spoke of improving emotional wellbeing by “going on a journey” with the patient, showing empathy and encouraging the patient to verbalise their emotional distress (R2.3) “You go a little deeper into the subject of anxiety, how they manage their problems” (Physician 3, female, interview three). However, other physicians spoke of requiring greater psychological resources in the outpatient clinic (R2.3) in order to help patients better manage the effect that the disorder can have on their psychological wellbeing “A psychologist in the outpatient clinic, yes, I consider it necessary, sometimes it is more psychological than psychiatric” (Physician 3, female, interview three).

One physician extended this further by suggesting that greater resources and support were needed for the carers of these patients as often family and carers have to manage the burden of the disorder alone without sufficient support.

In other diseases, or chronic pathologies ... the caregivers of the chronically ill, in short ... all these people are in their homes unattended and are facing situations as important as the death of a family member, or facing cancer.

(Physician 2, male, interview two)

This same physician stated that one method of overcoming this would be a training programme providing carers with knowledge regarding what to do and how to overcome these situations.

4.2.10.2. Adherence to treatment.

Quotations were coded under this subcategory if they referred to the importance of complying with the guidelines and treatment prescribed by the physicians, as well as the difficulties that physicians encounter when encouraging patients to comply to these.

Physicians stated that adherence to treatment varies from patient to patient with many individual differences such as age, gender, diagnosis, stigma and social roles affecting the level of compliance. Some physicians proposed techniques to overcome this such as making sure that the patient is actively involved from the beginning of the treatment (R2.3). Other strategies included providing patient information outlining healthier behaviours (R2.3), which can help to give patients a greater sense of control over their disorder “A patient that is told that they have a serious or potentially serious disease, but that it can be corrected with certain dietary and pharmacological measures, tends to become more involved” (Physician 2, male, interview two).

Additionally, other methods involve providing solutions to the patient to become more self-sufficient outside the consultation (R2.3) “Give them the tools...you have to do the diet, you have to empower yourself to exercise” (Patient 4, female, interview four). One physician also stated that it is important to provide the patient with the necessary tools regardless of their diagnosis, as it can be difficult for some patients to fully grasp the seriousness of the disorder “Fatty liver, which do not have any symptoms, which are asymptomatic diseases, have an impact on your health...it is important to give guidelines [outlining] healthy dietary

habits...you need to explain the importance and relevance of their pathology” (Physician 3, female, interview three).

4.2.11. Main Physician Theme Three: Health System.

This theme groups codes that refer to how healthcare resources affect the doctor’s work, and consequently the quality of care that patients receive. A total of five codes were extracted from this theme (see page 211 for a full list of the physician codes for theme three).

4.2.11.1. *Overload-consequences.*

The narratives from this subgroup refer to the consequences of having an overload of patients, and the effect that this has on the quality of care that they are able to provide.

Physicians speak of the difficulties in obtaining a balance between providing time for the patient “You try, more or less, to stick to what each one needs, not to stick to the schedule” (Physician 3, interview, three) and ensuring that they have enough time for each individual case “Of course, if you do not stick to the schedule, outside will be chaos” (Physician 3, interview, three). The lack of time available for each patient also has negative effects on the physician “Sometimes you feel bad because you see that you could do more but you cannot” (Physician 1, female, interview one). One physician stated that they felt that this also had consequences on the information they were able to extract from the patient “If there was more time I could find out more things” (Physician 1, female, interview one) which sometimes led to a less holistic understanding of the patient.

The high volume of patients appears to be particularly challenging in outpatient gastroenterology settings “I do not know if the gastroenterologist has 5 minutes per patient, or 10” (Physician 4, female, interview four). The problem of an excessive number of patients does not appear to be as apparent for other healthcare professionals “I have half an hour, I probably

do things that the gastroenterologist will not be able to do” (Physician 4, female, interview four). As well as in other healthcare settings “The GP, knows the patient, the patient's family, knows much more than what I can actually get out of my consultation” (Physician 1, female, interview one). There still appears to be a large gap in regards to resources in outpatient care compared to specialist care, which consequently can lead to difficulties in managing and treating patients (R2.3).

In a hospital, a specialist is seeing...20 or 25 patients in a week...in the outpatient clinic you are seeing a minimum of 100 patients a week, at least, so I think that also greatly influences the way patients are treated.

(Physician 2, male, interview two)

4.2.11.2. Lack of resources for mental health referral.

This subcategory refers to the absence of an effective path allowing patients to be referred from healthcare services to mental health specialists. Additionally, this subcategory refers to the lack of communication or coordination which can occur as a consequence of this.

Physicians state the difficulties that they have experienced when trying to refer patients from public healthcare services to mental health services (R2.3) “In the outpatient clinic, the truth is there is not much connection” (Physician 1, female, interview one). Additionally, opportunities to collaborate with mental health services appear to be limited “We are not well coordinated, we have only managed it once” (Physician 3, female, interview three)

From the interviews, there appears to be a need for better public health resources allowing physicians to better manage patients with mental health disorders. Physicians require better access to interventions and a more effective path that links them to mental health professionals (R2.3).

In fact, as far as I know, we cannot refer patients from specialized care to primary care, it has to go through the GP that is a great difficulty. Then the perception you have is that psychological, or psychiatric care in primary care, is not focused, it is not specialised.

(Physician 2, male, interview two)

One strategy that was proposed was clearer guidance regarding how the physician could assist the mental health professional and vice versa, as well as providing stricter criteria regarding the patients that should be referred.

5. Discussion

The main objective of the thesis was to firstly assess the individual benefits of implementing a short-term educational intervention or training programme for patients and physicians. An assessment was conducted, where an educational component had been implemented, in order to identify which techniques have been most beneficial in improving patient's QOL and symptom severity. Additionally, educational programmes and training opportunities were evaluated in order to ascertain whether they are readily available for physicians, as well as to understand the potential benefits they could have in positively influencing beliefs and attitudes (study 1). Additionally, the thesis aimed to advance our understanding regarding the differing relationship between patients and physicians in a primary care setting, to explore whether differences exist between patient groups and to establish if there is a relationship between these variables and psychological distress, physician satisfaction and QOL (study 2, stage one). Lastly, the thesis aimed to explore some of these discrepancies using a qualitative approach in order to understand better the perspectives of both the patient and the medical professional treating this subgroup of patients (study 2, stage two).

In regards to study 1, six interventions were found that outlined the effect of educational interventions on patient's QOL and symptom severity (O1.1). The use of patient educational programmes implementing aspects of the biopsychosocial model showed promising effects on QOL and symptom severity (R1.1). For example, the results showed that the intervention group had greater improvements in QOL than the controls after 12 months (Schaefer et al., 2013), and significant improvements in gastrointestinal symptom severity and depression (Labus et al., 2013) post intervention (R1.1). Furthermore, significant improvements were made in IBS-SSS (R1.1) in one study which introduced the brain-gut axis and the biopsychosocial model as a method of explaining FGIDs (Berens et al., 2018). However, whilst improvements were found for most patients, only five out of the six studies found improvements in QOL and

symptom severity for all patients (R1.1). Some reasons for these differences may have been due to specific patient characteristics as patients with higher QOL made less improvements in overall gastrointestinal symptom severity than those with low or moderate levels (R1.1). This suggests that short educational programmes or interventions may not benefit all patients, and this should be taken into account when designing future interventions with this subgroup of patients.

Regarding the second part of study 1, only two studies appeared to have explored educational or training programmes for physicians focusing specifically on beliefs and attitudes (O1.2). The research question was only partly supported as although both studies outlined the potential benefits that training and education could have on physicians (R1.2; Joyce et al., 2017; Warner et al., 2017) only one of the studies highlighted the benefits that this could have on both the physician's attitudes and beliefs (R1.2; Joyce et al., 2017). Whilst the studies reported on the potential benefits of a training or educational intervention, neither of the studies outlined an educational programme whereby the physician was directly involved. The limited intervention and training opportunities for gastroenterologists is supported by previous findings which assessed the availability of continuous medical education (O1.2). This found that only 33.5% doctors had attended a specific course on helicobacter pylori (*H. Pylori*) or dyspepsia during their career and only 389 (27.4%) in the last five years (McNicholl et al., 2019).

With regards to study 2, referring specifically to stage one 'analyses with incongruence as a dichotomous variable'. We found differences for all of the sociodemographic variables with the independent variable 'incongruence' (O2.1). The findings supported the first hypothesis as statistically significant differences were found between the incongruent and congruent groups for age, gender, educational level, marital and employment status (H1.1). Patients in the incongruent group were older, female, less likely to have a university degree or a higher educational qualification, to be married or in a stable relationship and to be in

employment. These results also mirror findings by Rodriguez et al (2017) as statistically significant differences were found for age, education, and employment. Interestingly the current study found statistically significant differences for marital status and gender which had not been found to be significant in previous research (Rodriguez-Urrutia et al., 2017).

Regarding the second research question, statistically significant differences between patients with incongruent appraisals with physicians (incongruent group) compared to patients with congruent appraisals with physicians (congruent group) on all types of psychological distress (O2.2). The hypothesis was supported as on average patients in the incongruent group scored higher on somatisation, anxiety, depression and overall psychological distress than patients in the congruent group (H1.2). These results are in line with previous research conducted in a tertiary care setting as higher values were found for patients in the incongruent group for somatisation and depression compared to the congruent group. However, previous research did not find any statistically significant differences between groups for anxiety (Rodriguez-Urrutia et al., 2017), which was not the case for the current research.

In relation to the third hypothesis, statistically significant differences were found between patients with a functional gastrointestinal diagnosis and patients with an organic diagnosis on all types of psychological distress (O2.2). The hypothesis was supported as on average patients with a functional gastrointestinal diagnosis had higher scores on somatisation, depression, anxiety and overall psychological distress than patients with an organic diagnosis (H1.3). This has been supported by numerous studies outlining the link between psychological factors, more specifically depression and anxiety, with FGIDs (Addolorato et al., 2008; Van Oudenhove et al., 2016).

In regards to the fourth hypothesis, physician satisfaction only differed between groups when comparing the two diagnosis groups (O2.2). Therefore, the hypothesis was only partially supported as no statistically significant differences in physician satisfaction were found

between patients in the incongruent group and patients in the congruent group (H1.4). On the other hand, statistically significant differences were found in levels of physician satisfaction between patients with a functional gastrointestinal diagnosis and patients with an organic diagnosis (H1.4). On average patients with a functional gastrointestinal diagnosis had lower physician satisfaction levels than patients with an organic diagnosis. This mirrors previous findings as patients with IBS who had moderate to severe disease severity were more frequently disappointed with their medical care. Additionally, two out of five patients with IBS stated that they were not at all satisfied with their care (Halpert et al., 2018). One reason for this may be due to a lack of patient-provider communication. A recent study which focused on patients with IBS indicated that the patient-physician relationship is increasingly being challenged by a number of factors such as a lack of emphasis on communication skills training, as well as time pressures to see more patients in shorter visits (Halpert et al., 2018).

Lastly, when referring to our final hypothesis for this analyses, this was partly support as statistically significant differences were found in psychological distress scores for both of the main effect hypotheses: type of appraisal and diagnosis (O2.3). Patients with a functional diagnosis had on average higher psychological distress scores in both appraisal groups than patients with an organic diagnosis (H1.5). However, patients with an incongruent appraisal with the physician had on average higher psychological distress scores even when controlling for diagnosis (H1.5). The interaction effect was not supported as no statistically significant interaction was found between incongruence and diagnosis for the psychological distress subscales, as well as for overall psychological distress (H1.5). This may indicate that these variables function separately in the development of psychological distress, as incongruence had a greater influence on psychological distress than diagnosis (O2.3). This also suggests that the presence of a functional diagnosis may not be a contributing factor to higher levels of incongruence with physicians. It may be the case that the differing understanding of the illness

that the patient has with the physician could affect the susceptibility of developing different types of psychological distress. These results are in line with previous research as patients with FGIDs receiving specialized care had a similar psychological profile to patients diagnosed with non-functional disorders such as gastrointestinal motor disorders (GMD; Eiroa-Orosa et al., 2016).

In regards to study 2, more specifically stage one analyses 'incongruence as a continuous variable', the first hypothesis was supported. We found differences between patients who had completed the study compared to those who had not completed the study (O3.1). The first hypothesis was supported as completers of the study were generally younger than patients who did not complete the study (H2.1). This is an interesting finding and does not appear to have been reported in previous studies with this subgroup of patients (Rodriguez-Urrutia et al., 2016). Differences were also found in other sociodemographic variables as a higher number of completers were female, were married or in a stable relationship and were in the follow-up consultation group. On the other hand, patients who completed the study were less likely to have higher education or a university degree and to be in employment (O3.1).

Regarding the second hypothesis, the first part of the hypothesis was supported as a positive correlation was found between incongruence and general psychological distress, as well as for each of the subtypes (H2.2). These results reiterate the findings with FGID and GMD patients whereby a strong link was found between incongruence and psychopathology in a tertiary care unit (Rodriguez-Urrutia et al., 2016). This has also been found to be the case in other chronic disorders, for instance one study found that discrepancies between patient with chronic depression and physicians contributed to higher levels of depressive symptomatology (Schrader, 1997). The second part of this hypothesis was also supported as a negative correlation was found between incongruence and the mental health component score (H2.2).

When making referring to the third hypothesis we expected to find higher incongruence scores for patients with a functional gastrointestinal diagnosis than patients with an organic diagnosis. As well as lower QOL for patients with a functional gastrointestinal diagnosis than patients with an organic diagnosis. This hypothesis was only partially supported, no statistically significant differences were found for incongruence between patients with a functional diagnosis and patients with an organic diagnosis (H2.3). Referring again to the research conducted by Rodriguez et al (2016), the presence of incongruence was more influential in the development of psychopathology than having a functional diagnosis or a GMD diagnosis (Rodriguez-Urrutia et al., 2016). This is in contrast to a study examining physician perceptions towards patients with FGIDs and patients with an organic diagnosis using out of hours telephone calls. Differing perceptions between physicians and patients were amplified for patients with an FGID (Dalton et al., 2004). It may be difficult to determine whether differences in results were due to the nature of the study, i.e., consultations were conducted over the telephone, rather than in person which was the case in our study.

The second part of the third hypothesis was supported as patients with a functional gastrointestinal diagnosis on average had lower QOL scores than patients with an organic diagnosis (H2.3). This supports much of the literature which has indicated that patients with a functional gastrointestinal diagnosis are more likely to have lower levels of quality of life (Choi & Jung, 2011; Koloski et al., 2000; Sperber et al., 2020). For example, studies have shown that patients with IBS often report significantly impaired quality of life not only compared to 'healthy' controls (Amouretti et al., 2006) but also in comparison to other chronic disease sufferers such as gastroesophageal reflux disease, asthma, migraines, diabetes and end-stage renal disease (Frank et al., 2002; Gralnek et al., 2000).

When referring to the fourth hypothesis, this hypothesis was not supported as incongruence was not negatively correlated with physician satisfaction (H2.4). The results

indicate that in general patients are satisfied with the care that they receive from physicians in primary care settings, which was further supported in the qualitative section of the current research. Additionally, this suggests that other factors may need to be considered when evaluating the satisfaction that patients have with their level of care. Some research has found that improved access to care was associated with patient satisfaction (Mehrotra et al., 2009; Polinski et al., 2016).

In relation to the fifth hypothesis of this subsection, we anticipated that there would be differences between males and females for incongruence, overall psychological distress, the different psychological distress subscales, physician satisfaction and quality of life (O3.2). The hypothesis was partly supported as females on average had higher incongruence and psychological distress than males, as well as lower quality of life scores than males (H2.5). This mirrors the current literature that have found gender differences, with women experiencing more severe IBS symptoms and lower QOL than men (Quigley et al., 2006; Simrén et al., 2001; Tang et al., 2012). Additionally, as in the current study, women tended to have more anxiety and depressive symptoms than men with IBS, although this has not been supported by all of the research (Lee et al., 2017). Lastly, no statistically significant relationship was found between gender and physician satisfaction (H2.5).

Regarding the second part of the fifth hypothesis, we aimed to identify the relationship that age has with the aforementioned variables (O3.2). This hypothesis was only partly supported. A statistically significant positive correlation was found between age and incongruence, as well as for age and physician satisfaction (H2.5). On the other hand, a negative relationship was found between age and overall psychological distress, which was also the case for the somatisation and anxiety subscales (H2.5). No statistically significant relationship was found between age and depression (H2.5). Additionally, the hypothesis was partly supported for age and QOL as a negative correlation was found between one of the QOL

subscales with age (physical health component score) whereas no statistically significant results were found for age and the mental health component score (H2.5). This is in contrast to previous research, as IBS affected QOL at all ages and in fact social functioning was on average better among older patients compared to younger patients (Minocha et al., 2006). One study explored this further and proposed that medical comorbidity may be more of an influential factor in mental and physical QOL. For instance, medical comorbidities may be perceived as less manageable among younger IBS patients, who may often face multiple roles and responsibilities and may be less prepared to cope. Conversely, older IBS adults might adjust more readily because they regard multiple medical problems as a normative part of the ageing process (Sarkisian et al., 2002).

Regarding the sixth hypothesis, we predicted that incongruence, age, gender, physician satisfaction and diagnosis would significantly predict psychological distress (H2.6). The hypothesis was supported as all the variables predicted psychological distress, in particular gender and incongruence (O3.3).

For the final hypothesis, we predicted that physician satisfaction, age, gender, and diagnosis would significantly moderate the relationship between incongruence and psychological distress (H2.7). This hypothesis was only partially supported as only a significant interaction was found between incongruence and age on psychological distress (H2.7). The strength of this relationship was found to be stronger for younger patients than older patients indicating that psychological distress may decrease with age (O3.4). Similar results were found for patients with IBS, with younger patients experiencing greater psychological distress than older patients (Schmulson-Wasserman & Saps, 2019; Thakur et al., 2016). One study which examined psychological distress in patients with cyclic vomiting syndrome also found that younger patients (25-35 years of age) were likely to suffer higher levels of psychological distress which could be explained by a greater number of uncertainties

and stressors during this time period. For example, this may include completion of education, career building and starting a family which may contribute to higher psychological vulnerability and distress (Taranukha et al., 2018). Therefore, it could be that different psychopathologies may be undetected and less recognised in younger patients than older patients.

Regarding the first research question of study 2 stage two, the focus group discussions provided an insight into the relationship that incongruent patients have with their consulting physician (R2.1). Additionally, the discussions indicated to what extent the health care system affects the communication they have with physicians (O4.1). In general, most patients were very satisfied with the care that they receive from their consulting physician, as well as with physicians from other specialities (R2.1). Most patients used positive language (e.g., “magnificent”) to describe their level of care which was reiterated across the different focus group discussions. Many patients stated that they had a strong rapport with the physician, felt valued, listened to and understood (O4.1). Patients also outlined that physicians provided a form of ‘patient education’ in the consultation through the use of recommendations, guidelines and advice which helped them to understand their diagnosis better and made them feel that they were less alone in the recovery process. On the other hand, a subset of patients showed frustration with the healthcare system as they described it as being “overcrowded” and the waiting times as being “lengthy” and “excessive” (O4.1). Consequently, this affected the amount of communication that some patients were able to have with their consulting physician, with some stating that they required more frequent contact. A previous study supports the need for a greater number of consultations as it found that a higher number of follow-up consultations were important for patient satisfaction three and six months after establishing care with a gastroenterologist (Singh et al., 2020).

From the focus groups discussions, it was clear that having a gastrointestinal disorder significantly impacted the daily life and functioning of incongruent patients (O4.2). Many patients spoke of the negative effect of having the disorder on their physical health, sleep patterns and eating habits (R.2.2). The most common area that was affected was their eating habits with many patients needing to change their routines as a method of better coping with symptoms, for example by limiting the number of times they eat outside the house and avoiding specific foods (R2.2). The deterioration of the above areas also influenced their quality of life, with some patients stating that this they had lower mental health (O4.2). Patients mentioned the link between their physical and emotional wellbeing with some experiencing pain and at the same time suffering from depression (R2.2). Patients also spoke of feeling more insecure and stressed, as well as having lower self-esteem (R2.2). Additionally, patients spoke of having worse or strained relationships with others due in part to having less interest in socialising and greater worries around food. Whilst patients acknowledged that having this disorder had been challenging, others spoke of using coping mechanisms as a method of functioning better (R2.2). For instance, through the use of mentalisation, acceptance and adapting their lifestyle.

In relation to the last hypothesis of study 2, through the physician interviews it was possible to identify some of the resources that are currently available for patients with incongruent appraisals with physicians, as well as areas that still require improvement (R2.3). From the physician interviews it was clear that certain components were considered key in the treatment process such as the following (a) patient-physician relationship (b) communication with professionals from other specialities and healthcare systems (c) multidisciplinary interventions and (d) implementing aspects from the biopsychosocial model.

Physicians also stated that focusing on the emotional wellbeing of the patient was essential when providing treatment to patients, regardless of the diagnosis (R2.3). However, physicians indicated that they required more training and a stronger link with mental health

services (R2.3). As a result, they found it challenging when recommending psychological services and encouraging patients to take part in psychological interventions. This is in accordance with previous studies which have found that many GPs feel that they lack the skills to provide appropriate psychotherapeutic interventions. In a recent analysis of videotaped consultations between GPs and patients with FSS it was found that GPs had a limited repertoire of strategies, felt insecure on which strategies may benefit individual patients and felt uncertain about how to support the patient in putting the advice into practice (Gol et al., 2019). One solution that has been proposed is the presence of a psychologist in the outpatient clinic (R2.3), which is still not an option that is provided in primary gastroenterology.

In relation to patients with FGIDs, greater time with this subgroup of patients was deemed as necessary. Due to the nature of FGIDs, providing a good explanation about their disorder and creating a good relationship with the patient was considered as more important than with other patients (O4.3). One reason for this was that the FGID diagnosis was often less straight forward than for patients with other gastrointestinal disorders and therefore greater collaboration is needed with the physician (O4.3). However, physicians also indicated that their resources were limited, with many not having enough time with this subgroup of patients thus making treatment more difficult (O4.3). This mirrors previous studies in which physicians in primary care specialties described how the pressure to provide a greater quantity of services effectively limited the time and attention that could be spent on each patient, thus deterring the physician from providing optimal care (M. W. Friedberg et al., 2014).

5.1. Strengths and limitations

Whilst the influence of incongruence has been studied in tertiary care settings (Rodriguez-Urrutia et al., 2016, 2017), the findings from this research have the potential to deepen our understanding of incongruity between patients and professionals in different

healthcare settings. To our knowledge this was the first study to explore incongruence on psychological distress in a primary care setting. Additionally, although previous research has indicated the negative effects of the presence of incongruence on several medical conditions such as multiple sclerosis (Rothwell et al., 1997) and asthma (Cowen et al., 2007), limited research has focused on the effect of incongruence on patients with FGIDs and patients with less severe medical conditions.

In addition, this was the first study to include a qualitative component for patients with incongruent views with physicians using this technique. Whilst surveys can identify gaps between health knowledge and health behaviour, only qualitative methods such as focus groups can actually fill these gaps and explain why these occur (Kitzinger, 1995). For instance, this technique may have helped to establish the patient's disease experiences and their views regarding the health system and services they receive (Murray et al., 1994). Therefore, this technique allowed us to ascertain some of the underlying reasons for high incongruent levels, as well as possible gaps that still exist which should be addressed in order to improve the care provided to patients and the support available to physicians.

This relatively novel approach could also serve as the basis for a future screening tool that allows for a better understanding between psychological distress, somatisation, and the continuation of disorders for patients with gastrointestinal disorders. Whilst routine screening for depression and anxiety is not required for this subgroup of patients, findings from a previous study highlighted the importance of screening patients with IBS for low mood and anxiety. This is because depression has been commonly identified as a predictor of poorer patient satisfaction in primary care and chronic pain (Singh et al., 2020). Regular screening tools and subjective evaluations that invite the patient to provide feedback regarding their disease and their HRQOL are invaluable in our understanding of the patient's functioning. Brief open ended questions such as 'How do your bowel symptoms interfere with your ability to do what

you want to do in your daily life?’ could provide gastroenterologists and primary care physicians with a more complete picture of the patient’s wellbeing, as well as additional information about their general clinical picture (Keefer et al., 2018; Krarup et al., 2015).

In relation to the limitations of the thesis, firstly due to the small number of papers included in the systematic review it may be difficult to draw conclusions regarding the most effective educational intervention for either patients or physicians. Additionally, when evaluating the findings the lack of a control group (Bengtsson et al., 2006; Håkanson et al., 2012; Ringström et al., 2009) and small numbers included in each condition may threaten the internal validity of the studies.

Secondly, due to the cross-sectional nature of the study it may be challenging to draw firm conclusions from the results. This may also lead to difficulties when establishing causal inference and exact FGID symptomatology. In a previous study, the prevalence of IBS and FD were stable over time when symptoms were assessed 12-20 months apart (Talley et al., 1992). However, other research has found that although the prevalence of these disorders remains stable, there was a considerable turnover in symptoms (Agréus et al., 1995). Results have indicated that much of the onset and disappearance of the disorders over time were due to subjects changing from one FGID to another rather than symptom resolution.

An additional limitation is that the use of some measures may have led to difficulties in obtaining accurate information regarding the impact of the disease. For example, the SF-12 is a general QOL measure, which makes it difficult to attribute poor scores to the GI disorder and is less likely to reflect treatment response. Whilst the KPS scale has been effective in previous studies conducted with FGID patients in tertiary care, it may be a questionable method for assessing patients with less severe symptoms such as those being seen in PCCs. It could be argued that this scale is more useful for patients with medical conditions that severely affect patients functioning in daily life such as advanced cancer patients.

The uniqueness of study 2 may be questionable as some of the methodology was based on previous research conducted in tertiary care centres. Similarly, to the present study, these studies examined incongruence between physician reports, the patient's functional ability and the patient's own perceptions. However, although some of the same methodology was adopted, the current study applied this method to a unique patient population (i.e., primary care patients) and implemented a qualitative component exploring the views of patients with incongruent appraisals with physicians, which has not previously been conducted.

5.2. Conclusions

The current thesis aimed to extend the research in the area of gastroenterology and patient-physician incongruence by incorporating it to other healthcare settings, identifying possible areas of improvement and establishing ways that we can apply the knowledge to future educational interventions. Based on the findings obtained from studies 1 and 2, we can conclude that given the effect of congruence on both the patient and physician that greater focus should be given to this when conducting group based educational programmes for patients, as well as when providing training and interventions for trainee gastroenterologists. The leitmotiv is thus to apply this knowledge to psychoeducation for patients and training for clinicians.

Referring specifically to study 1, this has provided us with a global perspective regarding the availability of educational programmes and the strategies that could most effectively be applied in real life clinical practice. The results from study 1 show some promising outcomes of implementing interventions for patients and physicians, especially in the case of patients. Although caution needs to be taken when drawing definite conclusions, patient educational programmes implementing components of the biopsychosocial model have been consistently useful in improving quality of life and symptom severity. On the other hand,

the findings from study 1 indicate that physician education and training opportunities are still limited and not commonly available to junior physicians. This can lead to greater difficulties when trying to effectively treat this subgroup of patients and can create anxiety surrounding how best to manage them.

Referring to Study 2, this aimed to delve deeper into the factors that may be affecting the patient-physician relationship, patient outcomes and the management of patients with gastrointestinal disorders. The main conclusion we can take from study 2 is the importance of congruence, (i.e., similar views) between patients and physicians regarding the patient's quality of life. The lack of congruence between the former and the latter should be considered as an important indicator of psychological distress. There are also a number of specific conclusions that can be made from Study 2, which have been listed below:

1. The results show a link between incongruent views and patient-physician expectations/beliefs and psychosocial distress. More importantly, incongruence has been found to have a greater explanatory power on psychological distress than any other variable.
2. Differing perceptions between patients and physicians may lead to different priorities for treatment. Therefore, having a better understanding of the factors that could be influencing this relationship may impact health and inform treatments. This was reiterated in the physician interviews which showed that patients often focused more on a biomedical solution, whereas physicians aimed to provide a more integrated approach.
3. Patients in the incongruent group did not have lower levels of physician satisfaction than patients in the congruent group. The results from the focus group have enriched our understanding further by identifying that satisfaction may also be inclusive of

the extent to which they are receiving continuity of care, an accurate assessment of their symptoms and frequent communication with their consulting physician.

4. FGID patients had higher levels of psychological distress and lower physician satisfaction levels than patients with an organic diagnosis. Physicians considered that this may be influenced by the number of consultations, which they indicate as key in the development of the patient-physician bond. Additionally, both patients and physicians stated that an increase in communication could also have positive effects on the patient's psychological wellbeing.
5. No interaction was found between diagnosis and incongruence suggesting that these variables function separately and are linked differently with psychological distress. Therefore, discrepant views between patients and physicians contribute to psychological distress regardless of the patient's diagnosis. In addition, this also suggests that psychological distress is present in both diagnostic groups, suggesting that the subjective understanding of the illness is an important component to consider.
6. Patients involved in the focus groups indicated that the gastrointestinal disorder affected many areas of their daily life, in particular their eating habits. Patients reiterated that they were highly satisfied with their consulting physician, as well as physicians from different specialities and multidisciplinary teams. They outlined that physicians used techniques in the consultation which led to improvements in their wellbeing. For example, the use of in-consultation 'patient education' through guidance, explanation and recommendations which helped them feel more accompanied in the recovery process. On the other hand, patients also stated their frustrations with the waiting lists and at times felt that these were detrimental in the treatment and recovery process.

7. Physicians stated the need for multidisciplinary interventions with a focus on providing emotional support to patients. Physicians spoke of the need for a greater number of mental health resources in the outpatient clinic and better links to mental health services. Due to the nature of FGIDs, greater time and resources are needed to effectively treat this subgroup of patients. Additionally, as a result of the complexity of the diagnosis an adequate explanation regarding their disorder which incorporates elements from the biopsychosocial model is considered necessary.

5.3. Applicability of findings to healthcare and practice

In regard to study 1, some key benefits have been found to providing educational opportunities for patients and physicians. In a recent study it was found that information was sometimes minimal and inaccurate for patients with IBS, especially regarding the causes and prognosis (Abouelala, 2021; Black & Ford, 2020). Therefore, providing education to patients about their illness early on in the consultation could be a key prognostic factor which may help with the outcome of the treatment.

When referring to study 2, our results show a strong relationship between having congruent views regarding quality of life and psychological distress. As incongruent appraisals between patients and physicians, and consequently psychological distress have been found to be present both in tertiary and primary care settings this may highlight the need for improved psychosocial assessment in gastroenterology (Keefer et al., 2008; Rodriguez-Urrutia et al., 2016). Additionally, an improvement in psychosocial assessment may not only help trainee clinicians to better detect psychological distress but could also provide clues in the prevention of future psychopathology, especially for younger patients.

In addition, the obtainment of physician satisfaction levels could aid physicians by providing them with a direct representation of how patients perceive their care experience. This

could help physicians better understand the areas of improvement and the areas of excellence. The use of patient perceptions is invaluable in the success of healthcare professionals (Singletary et al., 2017). Given our current climate, an improvement in patient-physician communication could be encouraged through ‘Remote Patient Monitoring’ (RPM; Riaz & Atreja, 2016). This strategy can benefit patients by promoting self-management between consultations and can help physicians visualize the patients’ health status (i.e., the frequency of pain days). This could assist them in their understanding of the type of intervention that should be implemented and the professionals that should be involved in the therapeutic process. This will also help to shift care from volume-based to value-based as RPM could lead to more effective healthcare delivery (Riaz & Atreja, 2016). Given the feedback obtained from the patient focus groups and physician interviews, better management of patient care is still a component that needs to be addressed in primary gastroenterology.

5.4. Future research

Firstly, as previously mentioned in our limitations, it would be useful to apply disease specific questionnaires as they have proven to be useful clinical aids for quantifying the current impact of the disease on patients’ lives (Irvine, 1999; Patrick et al., 1998). Additionally, other measures such as the ‘Millon Clinical Multiaxial Inventory-III’ (MCM-III) could help to detect possible personality patterns and clinical syndromes providing an insight into at risk groups. Previous work using the MCM-III found that excessive patient-initiated consultations was associated with dependency, compulsivity, anxiety, and major depression (Gomà-i-Freixanet et al., 2019). Therefore, for future research it would be beneficial to focus on identifying frequent attenders in primary care due to the link this has with psychological and psychiatric factors. Frequent or persistent attenders at PCCs are more likely to report psychological distress (Vedsted et al., 2001), depressive and somatoform disorders, as well as elevated health anxiety

and hypochondriacal beliefs (Gili et al., 2011; Jyväsjärvi et al., 2001; Smits et al., 2014). Findings have shown that certain demographic groups are more likely to be at risk of becoming frequent attenders. For instance, they are more likely to be elderly women who are socioeconomically disadvantaged, unemployed, not active in the workforce or are an immigrant.

Whilst our research findings have allowed us to identify the cross-sectional nature of the relationship between incongruence and physician satisfaction, perhaps the lack of a significant relationship between the two aforementioned variables in study 2 was due to the nature of the research. A longitudinal study controlling for the number of consultations with the physician could provide us with a better insight into the relationship between incongruence and physician satisfaction. Additionally, whilst previous research has suggested that satisfaction is a relatively stable construct, there have been contradictory results regarding whether satisfaction improves over time. Our results indicated that the ‘follow-up’ group (i.e., this was not their first contact with the physician) had slightly higher levels of physician satisfaction compared to patients who were seeing the physician for the first time. In one study it appears that after two weeks satisfaction was significantly lower compared to immediately after the initial consultation (Kortlever et al., 2019) which contradicts the findings of another study (Jackson et al., 2001). According to some studies, this could be because immediately after the consultation the patient’s level of satisfaction is strongly influenced by patient-doctor communication, whereas after two weeks the patient’s presenting symptoms have a much greater effect on satisfaction. Additionally, it has been found that at all time points, satisfaction appears to be influenced by age and functional status (Jackson et al., 2001). Therefore, future research could explore this relationship further and better control these variables to understand the evolution of the digestive disorder and the care relationship.

A further line of enquiry could be to implement an educational intervention for trainee gastroenterologists. Even though some improvements from guidelines have been partially incorporated, it appears to be the case that the implementation of recommendations can sometimes be delayed. This is based on recent literature which has found gaps in the implementation of specific continuous medical education. Although this has been reported as one of the main factors explaining correct implementation and adherence to recommendations, only a third (34%) of physicians had received specific education on H. Pylori and dyspepsia (McNicholl et al., 2019). In one study an educational session with HCPs provided them with an insight into IBD risk factors, prevalence and the effect of anxiety and depression on this subgroup of patients. Additionally, HCPs were taught about the potential advantages of using the 'Patient Health Questionnaire 4' (PHQ-4) to screen for anxiety and depression. The findings indicated that there was a statistically significant increase in the number of patients being screened for depression by physicians post intervention, as well as the number of referrals to psychological services (Molina, 2019). This technique has yet to be applied to other specialities and for different subgroups of patients (i.e., patients with FGIDs). The results from the current thesis also indicate that there is still a need for training in the detection of anxiety and depression. Additionally, training should focus on helping physicians become more aware of the reasons for why certain patients have lower quality of life than expected and the psychological distress that they may be experiencing as a result of this. This would work towards the concept of congruence (i.e., having more similar views) with patients regarding their quality of life, as well as enable them to recognise the psychological effect that debilitating pain and physical deterioration may be having on the patient.

The second part of the intervention could involve both trainee gastroenterologists and patients with FGIDs. Research has shown that structured education can reduce symptoms in patients with FGIDs (i.e. such as for patients with IBS) but yet the availability of these

interventions are limited (Lindfors et al., 2020). A recent study providing education online or in person giving them the opportunity to communicate with a nurse and a dietician found small within-group effects on IBS severity and IBS related QOL from baseline to post treatment assessment. To our knowledge this has yet to be applied jointly with trainee gastroenterologists. The implementation of an educational intervention, focusing specifically on promoting congruent views between patients and physicians regarding the patient's quality of life, could be beneficial to both patients and physicians. This could encourage greater self-management by patients with FGIDs and provide physicians with the resources to effectively manage this subgroup of patients.

Lastly, the final part of the intervention would be to implement an educational intervention for carers and families of these patients. This was identified by one of the physicians in the interviews as a component that is still not readily available, yet families and carers often do not have adequate support and often take on the burden of the symptoms.

The first step to achieving the above interventions would be to recruit a committee of experts and experienced gastroenterologists, as well as other medical professionals such as psychologists and nutritionists in order to oversee the creation of the materials.

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7. Appendices

7.1. Appendix A

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A systematic review outlining the impact of education on patients and physicians in gastroenterology

Alicia Georghiades and Francisco José Eiroa-Orosa

Department of Clinical Psychology and Psychobiology, School of Psychology, Neuroscience Institute, University of Barcelona, Spain

Correspondence

alicia.georghiades5@gmail.com; fjeiroa@gmail.com; feiroa@ub.edu

A systematic review outlining the impact of education on patients and physicians in gastroenterology

ABSTRACT

Functional gastrointestinal symptoms (FGIDs) refer to a noticeable change in the body that is reported by the patient as being different from normal. FGIDs can have a significant impact on the patient's quality of life by interfering with daily functioning. The primary objective of the current paper was to identify short-term educational interventions for patients diagnosed with FGIDs and medically unexplained symptoms. This is with the aim of assessing its effectiveness on patient's quality of life and symptom severity. The second objective was to establish the current educational programmes and training opportunities available for physicians working with this subgroup of patients. This is in order to ascertain if these could change negative physician beliefs and attitudes. Databases such as PubMed and Google Scholar were searched from November to February 2018. A total of eight interventions were found which were evaluated using the Behavioural Change Techniques Taxonomy. Short-term educational programmes combining the use of lectures and practical sessions were found to be the most effective in improving patient quality of life and symptom severity. Managing patient exposure through the use of problem-based learning was considered the most effective teaching method for trainee physicians and could help to prevent the internalisation of negative attitudes. Definite conclusions about the effectiveness of patient and physician interventions are difficult to ascertain due to the small number of studies found and the high risk of bias. Future research should focus on providing a more unified approach to the management of this subgroup of patients.

KEYWORDS

Functional gastrointestinal disorders; medically unexplained symptoms; quality of life; physician attitudes; early education

Introduction

Functional Gastrointestinal Disorders (FGIDs) recognized by morphologic and physiological abnormalities often include a combination of motility disturbance, visceral hypersensitivity, and altered mucosal immune function, gut microbiota, and central nervous system processing (Drossman, 2016; Jones et al., 2007). The Rome IV criteria classify FGIDs as disorders based primarily on symptoms rather than physiological criteria. Functional gastrointestinal symptoms refer to a noticeable change in the body that is reported by the patient as being different from normal, which may include nausea, pain and vomiting (Drossman, 2016). FGIDs can have a significant impact on the patient's quality of life by interfering with daily functioning, leading to work absenteeism and a decreased involvement in social and leisure activities (Riehl et al., 2015b).

In an integrative attempt, the biopsychosocial model (Engel, 1977) outlined the influence that early life, psychological stress, and other psychosocial factors can have on the development of the illness. For instance, a person's genetic composition may lead to a greater susceptibility of developing the illness which may be exacerbated depending on the individual's response to stress and exposure to psychosocial factors. As with any chronic illness, this may have psychosocial consequences which perpetuate and amplify the symptoms by affecting one's general wellbeing, daily functioning, and sense of control (Drossman, 2016). Since the biopsychosocial model, several models have been proposed to help patients and physicians understand more clearly the way in which the body and illness function as a whole.

Patient education

The Clinical Care model is an educational framework which is based on the premise that providing patients with the opportunity to share illness experiences with others, combined with professional scientific knowledge, can facilitate learning experiences and enable individuals to find useful strategies for managing their everyday illness symptoms (Håkanson et al., 2012).

Research has outlined several benefits from patient education programmes, such as an improvement in symptoms and better quality of life. Findings from one patient's educational programme indicated that patients were more self-secure, were better prepared to manage their symptoms and maintain their well-being after taking part. This was in part due to the better understanding they had regarding their illness, as well as the opportunity to listen to the illness stories of others (Håkanson et al., 2012).

A study using the concepts proposed by the self-efficacy theory and the biopsychosocial model found that patients made positive improvements after participating in an 'Irritable Bowel Syndrome' (IBS) school. These patients learnt about mechanisms related to enhancing skills mastery, reinterpretation of physiological symptoms, and modelling (Bandura, 1977; Lorig, 1996). Patients were also provided with the opportunity to share their own experiences with other patients regarding methods and strategies that they had found to be useful when managing their symptoms. The education group displayed greater reductions in IBS symptom severity and gastrointestinal specific anxiety, as well as greater improvements in the perceived knowledge of IBS. Additionally, several aspects of health-related quality of life (QOL) were significantly improved after the group education (Ringström et al., 2010).

Physician education and training opportunities

Much of the research has outlined that the management of patients with medically unexplained symptoms can be challenging and for some trainee physicians can act as a significant source of anxiety, particularly around missing serious pathology (Warner et al., 2017). Whilst doctors have adopted a variety of approaches to manage these patients, for instance by exploring psychological, social and physical factors (Warner et al., 2017) clinician attitudes towards patients still vary considerably. This is because some physicians find managing these patients as a positive challenge while others find the process to be exhausting and time-consuming (Warner et al., 2017). Inconsistencies between different clinicians' risk portraying

contradictory messages to the patient and this can lead to a loss of the patient's confidence and trust.

The literature on how medical students are trained to manage patients with medically unexplained symptoms is very limited (Joyce et al., 2017). One survey given to different UK medical schools found that functional syndromes were entirely absent in some medical curricula, and if they were present, this typically accounted for less than a day of teaching (Howman et al., 2012). One study outlined that brief training given to medical undergraduates in irritable bowel and chronic fatigue syndromes led to improvements in student knowledge and attitudes towards these patients (F. Friedberg et al., 2008).

The aim of this paper is to systematically review the state of the scientific literature regarding the current educational interventions available for this subgroup of patients. Additionally, it aims to identify if educational interventions could affect symptom severity and quality of life. The review also aims to assess current interventions and training opportunities for physicians working with this subgroup of patients. This was in order to establish if this could lead to more positive beliefs and attitudes.

Materials and methods

PROSPERO approved our protocol before data analysis (Eiroa-Orosa & Georghiades, 2019). We conducted this systematic review adhering to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Moher et al., 2009) guidelines (see supplemental document one).

Participants

Inclusion and exclusion criteria for the studies were developed and agreed upon by both authors before the review process. Patient intervention studies had to meet the following criteria: (a) Patients were aged ≥ 18 years at baseline (b) gastrointestinal diagnosis and (c) refer to a short-term health educational or psychoeducational intervention. Physician studies were included

based on the following: (a) The physician/gastroenterologist treated patients with FGIDs or medically unexplained symptoms and (b) the study referred to educational or training opportunities. All the studies had to be published in English.

Search strategy for identifying potential studies

We searched PubMed and Google Scholar from November to February 2018 (see supplemental document two). The search strategies included the following keywords; gastroenterology, health education, psychoeducation, psychosocial interventions, rumination syndrome, irritable bowel syndrome, functional dyspepsia, patients with somatisation, secondary care, and physicians. We excluded animal studies, meta-analyses, systematic reviews, book chapters, symposiums, specialised psychological interventions, and interventions involving paediatric patients. We believe that the characteristics and contexts of interventions for paediatric patients are distinct enough to warrant a different review.

Data collection and analysis

Selection of studies

Initially, studies from PubMed were identified using an online screening database called Rayyan, which allowed for the screening of titles and abstracts. The whole selection process was recorded in a separate excel database accessible to both authors. One author (AG) independently screened and recorded the titles and abstracts for selection. Both authors (AG and FJEO) independently assessed the articles that should be selected for the review.

Data extraction

In this review, we conducted a narrative synthesis for each study. The initial step involved conducting a preliminary synthesis which was implemented by one author (AG). The preliminary synthesis involved grouping the studies and producing a tabulation of the results which involved the obtainment of the following characteristics of each study: participant demographics, intervention length, content and groups, outcome and conclusions. The second

author (FJEO) reviewed the content of the table and critically assessed each study to ensure it met the inclusion criteria.

Behavioural change techniques taxonomy coding

Each of the studies was coded using the Behavioural Change Technique Taxonomy (BCT ; Michie et al., 2013). Using a similar technique that has previously been conducted, behavioural interventions were coded if they targeted patient's behaviour or healthcare provider's behaviour (Presseau et al., 2015).

One of the authors (AG) individually assessed each intervention using the guidelines and examples adopted in previous studies (Kebede et al., 2017; Michie et al., 2015; Presseau et al., 2015). In the case that interventions were described as involving the provision of 'education' without any additional information, the BCT was coded as *information about health consequences* and *instruction on how to perform the behaviour*. Additionally, when interventions were described as providing 'training' without further detail, the training intervention was coded as *instruction on how to perform the behaviour*. The interventions were then further assessed by the second author (FJEO). Any discrepancies were resolved through discussion.

Assessment of the quality of the methodology

The Quality Assessment Tool for Quantitative Studies was used to assess the quality of the methodology of each study included (Practice, 1998). This tool was used as it examines the characteristics of both randomized and nonrandomized designs. Both of the researchers involved in the study evaluated each study for potential bias. Any discrepancies were discussed until a consensus was reached. Raters evaluated the articles on the following characteristics (a) selection bias (b) study design (c) confounders (d) blinding (e) data collection methods and (f) withdrawals and dropouts. Each study received a global rating of either 'Weak', 'Moderate' or 'Strong'.

Results

Study selection

The database search provided 6,141 related studies, of which 33 articles were potentially relevant. After screening the full text, a total of 25 were excluded due to not meeting the inclusion criteria (see Figure 1 for full details). A total of eight articles were considered to be suitable for this review (Bengtsson et al., 2006; Berens et al., 2018; Håkanson et al., 2012; Joyce et al., 2017; Labus et al., 2013; Ringström et al., 2009; Schaefer et al., 2013; Warner et al., 2017).

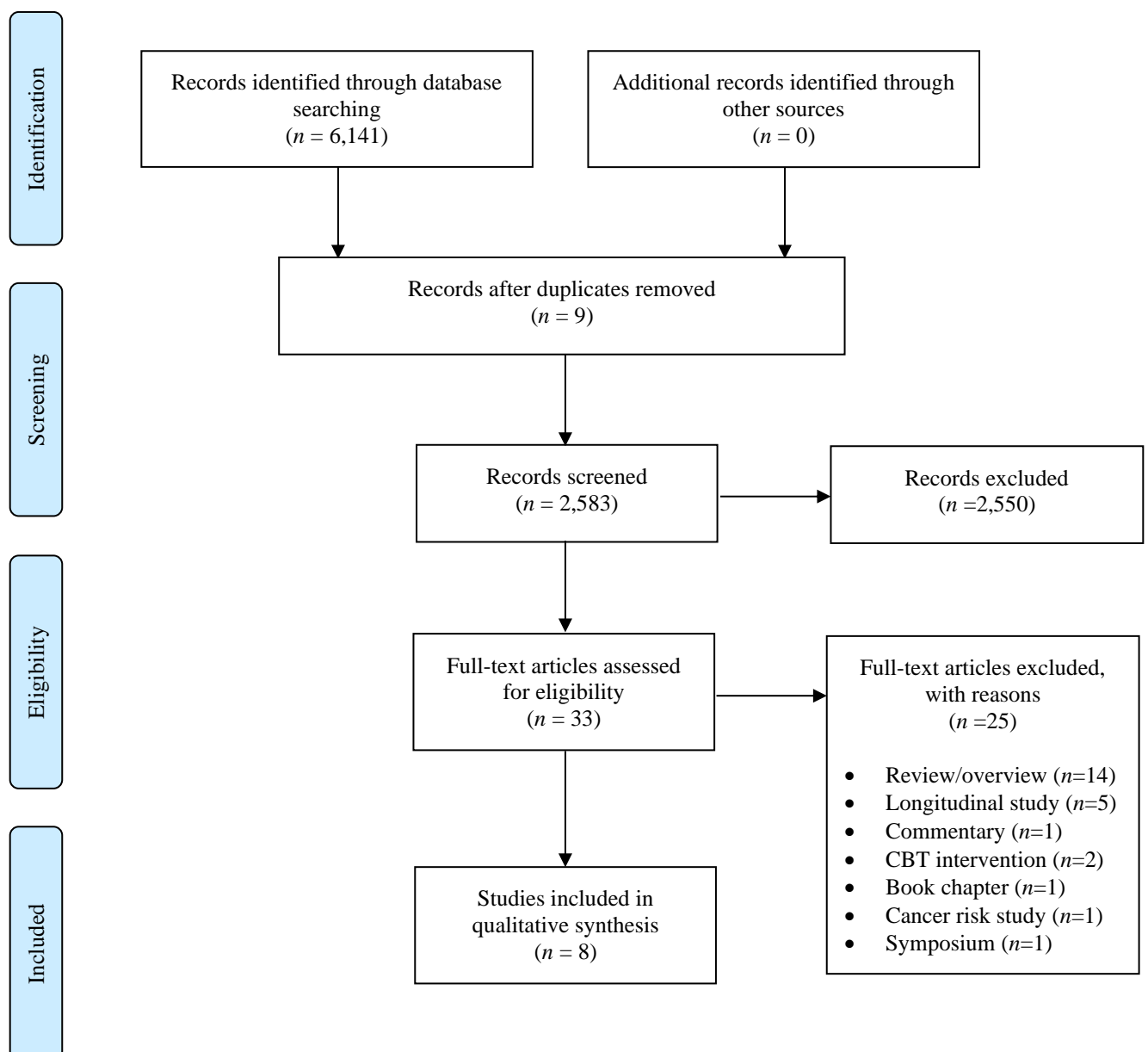


Figure 1. Flow diagram of the study selection process

Patient intervention findings

Few effective short-term educational programmes were found for patients with functional gastrointestinal disorders and medically unexplained symptoms (see table 1). From the studies identified, it was found that the most effective method for improving quality of life and symptom severity was group-based educational programmes combining lectures and practical sessions.

Short-term educational programmes

The first study used a course of instruction which involved an educational programme consisting of four sessions. The findings showed that when providing information to women with IBS on topics such as medical care and stress management, they perceived less pain, achieved more vitality, and experienced a higher quality of life (Bengtsson et al., 2006). Improvements were also found from baseline to 12-month follow-up in abdominal pain and vitality.

The second study showed that after a five-day patient educational programme that overall symptom severity of patients with IBS was reduced (Håkanson et al., 2012). The participants scored their symptoms and the overall influence of IBS on everyday life as being significantly lower after the education programme. Additionally, improvement in symptom severity also led to better coping strategies (Håkanson et al., 2012).

In a similar study conducted by Ringström and colleagues (2009) a six-week IBS school was implemented based on the self-efficacy theory. There was a statistically significant reduction in gastrointestinal symptom severity, which was indicated with lower scores on the IBS severity scoring system after 3 and 6 months (Ringström et al., 2009). Additionally, statistically significant improvements were found in health related QOL which were found on

several domains of the SF-36, as well as on both the physical and mental summary scores after an educational intervention (Ringström et al., 2009).

Furthermore, one study used a collaborative group intervention for patients with medically unexplained symptoms. There were between-group effects for improvement in symptom severity that lasted 12 months, but the effect lacked significance. Additionally, there were between-group effects for the mental domains of vitality and emotional role functioning and among the SF-36 physical domain of general health perceptions. Patients in the intervention group also reported significantly greater improvements in mental quality of life than the controls at 12 months (Schaefer et al., 2013).

Psychoeducational interventions

The study by Berens et al (2018) involved a multicomponent group therapy intervention. This involved integrating and combining evidence-based psychodynamic therapy with psychoeducation, gut-directed hypnotherapy, and treatment elements from cognitive behavioural therapy in a disorder orientated manner. The disorder orientation was provided by introducing the brain-gut axis as a bio-psycho-social explanatory model for FGIDs. The results from the 'Irritable Bowel Severity Scoring System' showed that IBS symptom severity improved within the intervention group (Berens et al., 2018).

The study by Labus et al (2013) aimed to evaluate the effectiveness of a psychoeducational intervention on IBS symptoms. Sixty-nine IBS patients were randomised to an intervention or wait-list control group. Patients who took part in the intervention showed statistically significant higher improvements in gastrointestinal symptom severity, visceral sensitivity, depression and quality of life post intervention. Additionally, patients who received the intervention demonstrated higher QOL scores than controls at the end of the study, which was also the case during the 3-month follow-up. Interestingly, the intervention did not lead to higher levels of QOL for those patients with high baseline levels of IBS-QOL. Whereas for

patients who were classified as having an 'average' level of QOL, a lower score for severity in symptoms was found in the intervention group than in the control group (Labus et al., 2013).

Physician intervention findings

Few studies have outlined training opportunities and educational interventions for physicians working with this subgroup of patients (see table 1). A patient-centred approach and managed patient exposure were found to be the most effective methods of changing beliefs and attitudes.

Qualitative interviews with physicians

During the interviews conducted with physicians and gastroenterologists, common attitudes were found regarding the management of patients. For example, some of the key findings were that most patients with IBS should and can be managed by primary care physicians and that IBS patients require a patient-centred approach.

Whilst variations were found in the approach used during consultation, both primary and secondary-level care clinicians emphasised the importance of good communication between clinicians and patients, as well as the importance of providing the patient with a clear explanation of their IBS symptoms. Regarding the development of their personal approach towards managing these patients, many physicians spoke of learning by example from different colleagues, whilst others spoke of learning from their own mistakes. A reoccurring theme from nearly all the physicians interviewed was that they had received little or no teaching during their training and many relied on informal 'on the job' experience (Warner et al., 2017).

In a study conducted with medical educators, some solutions and recommendations were outlined that could address training limitations. The first recommendation was to address negative attitudes and behaviour by focusing on the tutors' understanding regarding patients with medically unexplained symptoms, as well as sharing good practice and supporting trainee physicians to think critically. By doing so, educators have the chance to help trainee physicians understand patient's frustrations and are less likely to internalise the negative attitudes related

to this subgroup of patients. The second recommendation outlined the importance of encouraging students to learn through ‘managed patient exposure’. This involves providing trainee physicians with an insight into the experiences of the patients and carers. This could convey to the trainee physician the impact that these disorders have on the patient, as well as the most appropriate method of working with these types of patients. For instance, one recommendation that was provided involved evidence-based guidelines (Joyce et al., 2017).

Table 1. Overview of the studies included in the systematic review.

Author	Participant demographics	Intervention length, content and groups	Outcome	Conclusions
1. Bengtsson et al. (2006).	Patients with irritable bowel syndrome (IBS)	<ul style="list-style-type: none"> • Twenty nine women with IBS participated in a programme of instruction <p>The women also completed the Gastrointestinal Symptom Rating Scale and the Psychological General Well-being Index</p>	Twenty three of the women completed the questionnaires 12 months after the course. There were improvements in abdominal pain, vitality, as well as a reduction in the number of visits to physicians and dieticians.	Information related to the disease may help women with IBS to perceive less pain and more vitality and thereby experience a better quality of life.
2. Berens et al. (2018).	Patients with IBS	<ul style="list-style-type: none"> • Two hundred and ninty four patients (220 had IBS; 144 diagnosed with SAD). • Thirty patients consented to participate (group intervention n=16) and the wait-listed control condition (n=14). 	The group intervention was not significantly superior to the wait-listed control condition. Effect size for between-groups at the end of the treatment (post) was moderate.	The integrative group intervention for IBS proved to be acceptable and feasible in an interdisciplinary tertiary care setting.

3. Håkanson et al. (2012).	Patients with IBS	<ul style="list-style-type: none"> • Thirty one participants • Focus group interviews 	<p>Four patterns were found to be important;</p> <p>a) Being part of a safe community</p> <p>b) Learning about oneself through others</p> <p>c) Understanding and controlling the body and illness as a whole</p> <p>d) Being outside of the community</p>	<p>The combination of reciprocal sharing of experiences and the provision of professional scientific knowledge during the patient education programme together contributed to a readiness to improve well-being in everyday life.</p>
4. Joyce et al. (2017).	Medical educators from different UK medical schools	<ul style="list-style-type: none"> • Twenty-eight medical educators from 13 different UK medical schools • Semi-structured interviews 	<p>Barriers to implementing functional syndromes (FS) training are beliefs about the complexity of FS, tutors' negative attitudes towards FS, and FS being perceived as a low priority. They recommended that students learn about FS through managed exposure but only if the tutors' negative attitudes and behaviours are also addressed.</p>	<p>Negative attitudes towards FS by educators prevent designing and delivering effective education</p> <p>There is a need to implement FS training, but recommendations are multifaceted.</p> <ul style="list-style-type: none"> • There needs to be an increase in liaison between students, patients and educators in order to develop more informed and effective teaching methods for trainee physicians regarding FS
5. Labus et al. (2013).	Patients with IBS	<ul style="list-style-type: none"> • Sixty nine patients were randomised to the intervention (n=34) or to the wait-list control group (n=35) 	<p>Patients in the intervention showed significant improvement on gastrointestinal symptom severity, visceral sensitivity,</p>	<p>A brief psycho-educational intervention is effective in changing cognitions and fears regarding the symptoms of IBS and these changes are linked to improvements in symptoms and quality of life.</p>

6. Ringström et al. (2009).	Patients with IBS	<ul style="list-style-type: none"> • Twelve patients (5-7 in each group) • Five different health care professionals were involved in the education • Six weekly 2 h sessions 	depression and QOL post-intervention and these were maintained at the 3-month follow-up.	Patients were satisfied with the IBS school. The gastrointestinal symptoms, health related quality of life and knowledge about IBS improved significantly after the education.	This study indicated that an IBS school seems to be a useful method of meeting the needs of patients and providing them with information about IBS and could help to improve the patients' gastrointestinal symptoms, health related quality of life and knowledge about IBS.
7. Schaefert et al (2013).	Patients with medically unexplained symptoms	<ul style="list-style-type: none"> • Three hundred and four patients (170 intervention group; 134 in the control group). • Ten weekly group sessions and two booster meetings 	<ul style="list-style-type: none"> • There was a significant reduction in somatic symptom severity at 6 months, but which lacked significance at 12 months. • Between-group effects indicated less health anxiety, less psychosocial distress, and fewer GP visits. 	Collaborative group interventions led to meaningful improvements in mental but not physical quality of life. This has the potential to bridge the gap between general practice and mental health care.	

8. Warner et al. (2017).	Physicians working with patients in secondary care	<ul style="list-style-type: none">• Twenty consultants and training-grade physicians working in cardiology, gastroenterology, rheumatology and neurology• In-depth interviews with 20 physicians, 11 consultants, and 9 specialty trainees.	There was considerable variation in how the physicians approached patients who presented with medically unexplained symptoms. Physicians reported little or no formal training in how to manage these types of patients. Physicians described learning from their own experience and from senior role models.	There is a need for serious consideration as to how the management of patients with medically unexplained symptoms are included in medical training and in relation to the planning and delivery of services.
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Content analysis of interventions using the behavioural change techniques taxonomy

As seen in Table 2, each of the interventions had addressed at least one of the BCT categories. Of the eight studies included in the current systematic review, six had implemented clear BCTS. The two physician studies had addressed the need for training opportunities; however, they did not provide details outlining the intervention. As a result, both were coded as ‘instruction on how to perform the behaviour’.

Quality ratings of the included studies

Table 3 demonstrates the methodological quality of the studies across a range of dimensions (Practice, 1998). Overall, one study received a strong global rating (Schaefer et al., 2013), two studies received a moderate global rating (Berens et al., 2018; Labus et al., 2013) and five studies received a weak global rating (Bengtsson et al., 2006; Håkanson et al., 2012; Joyce et al., 2017; Ringström et al., 2009; Warner et al., 2017).

Discussion

The present systematic review helped to identify short-term educational interventions for patients with gastrointestinal disorders and with medically unexplained symptoms. Short-term educational programmes have been used to increase knowledge, teach simple self-management strategies, and decrease symptom-related fears (Ringström et al., 2009, 2010).

However, a limited number of studies have implemented educational programmes focusing on reducing symptom severity and improving quality of life for this subgroup of patients (Bengtsson et al., 2006; Berens et al., 2018; Håkanson et al., 2012; Labus et al., 2013; Ringström et al., 2009; Schaefer et al., 2013). A total of six interventions were found, with the majority implementing group-based educational programmes carried out by a number of different healthcare professionals.

Additionally, only a small number of studies appear to have explored educational or training programmes for physicians working with this subgroup of patients. Based on the few studies that were identified, it appears that little or no formal training is provided to physicians and that recommended strategies to use with patients are inconsistent. One study outlined some possible barriers that could be preventing the implementation of training such as beliefs about the complexity of functional syndromes, tutor's negative attitudes towards functional syndromes, and being perceived as a low priority for the curriculum (Joyce et al., 2017). One solution that has been proposed to overcome this barrier is to provide empowering explanations which have already been positively received by patients (Salmon, 2007).

Limitations

Our review is not without its limitations. Due to the small number of papers included, it may be difficult to draw conclusions regarding the most effective educational intervention for patients and physicians. Additionally, the lack of a control group in some of the studies (Bengtsson et al., 2006; Håkanson et al., 2012; Ringström et al., 2009) and the small numbers included in each condition may threaten the internal validity of these studies.

Table 2. Content analysis of the interventions using the BCT

BCT's identified (n=8)	Bengtsson et al (2006)	Berens et al (2018)	Håkanson et al (2012)	Joyce et al (2017)	Labus et al (2013)	Ringström et al (2009)	Schaefer et al (2013)	Warner et al (2017)
Antecedents (12.6)								
Feedback and monitoring (2.3)								
Goals and planning (behavior) (1.1)								
Goals and planning (outcomes) (1.3)								

Natural consequences (5.3)			■				
Shaping knowledge (4.1)				■	■	■	■
Social support (3.3.)		■	■				■

Table 3. A summary of the quality ratings of the included studies

Source	Global Rating	Selection Bias	Study Design	Confounders	Blinding	Data Collection Method	Withdrawals and Dropouts
Bengtsson et al, 2006	Weak	Moderate	Moderate	Weak	Weak	Strong	Strong
Berens et al, 2018	Moderate	Moderate	Strong	Strong	Weak	Moderate	Strong
Hakanson et al, 2012	Weak	Moderate	Weak	Weak	Weak	Weak	N/A
Joyce et al, 2017	Weak	Strong	Weak	Weak	Weak	Weak	N/A
Labus et al, 2013	Moderate	Moderate	Strong	Strong	Weak	Moderate	Moderate
Ringström et al, 2009	Weak	Moderate	Moderate	Weak	Weak	Strong	Strong
Schaefer et al, 2013	Strong	Moderate	Strong	Strong	Strong	Strong	Strong
Warner et al, 2017	Weak	Moderate	Weak	Weak	Weak	Weak	N/A

Conclusions

Patients with FGIDs and medically unexplained symptoms often find it difficult to manage their symptoms, which can have negative effects on their quality of life. Similarly, physicians

may also find it a challenging experience with many lacking appropriate guidance and resources.

The use of patient educational programmes shows promising effects with 5 out of 6 studies reporting benefits to both quality of life and symptom severity. However, the effects of these interventions are moderated by weak or moderate quality ratings, thus making it difficult to draw definite conclusions.

Based on the findings, there appear to be variable approaches to managing patients with FGIDs and medically unexplained symptoms. Future research should focus on providing a more unified approach by focusing on symptom management rather than causes, and by sharing good practice techniques.

Data availability statement

Data sharing is not applicable to this article as no new data were created or analyzed in this study.

Disclosure statement

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Supplemental document one



PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	1
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	1-3
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	3
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	3
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	3-4
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	3
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	In supplemental

			document 2
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	4
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	4
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	N/A
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	4-5
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	N/A
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	4

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	4-5
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	5 (see figure 1)
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	9-10 (table 1)
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	5-7
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	N/A

Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	N/A
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	12 (In table 3)
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	N/A
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	8
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	8-12
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	12
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	13

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

Supplemental document two

The electronic search strategy performed in PubMed.

	Search strategy	Results
S2	"Health education in Gastroenterology"	2.391
S2	"Psychoeducation in Gastroenterology"	6
S2	"Psychoeducation for patients with IBS"	3
S2	"Psychoeducation in irritable bowel syndrome"	4
S2	"Health education to improve IBS symptoms"	11
S2	"Health education for patients with Inflammatory and Functional Gastrointestinal Diseases"	14
S2	"Health education for patients with bowel incontinence"	138
S2	"Health education for patients with functional gastroenterology disorders"	53
S2	"Health education for gastroenterologists in secondary care"	7
S2	"Health education for patients with functional somatic symptoms"	38

S2	Psychosocial interventions for patients with functional dyspepsia	3
S2	Psychohealth education for patients with irritable bowel syndrome	3

7.2. Appendix B

ESCALA DE KARNOFSKY

CATEGORÍAS GENERALES	GRADO	ACTIVIDAD
Capaz de realizar actividades normales, no requiere cuidados especiales	100	Actividad normal. Sin evidencia de enfermedad
	90	Actividad normal. Signos y síntomas leves de enfermedad
	80	Actividad normal con esfuerzo. Algunos signos o síntomas de enfermedad
Incapaz de trabajar, puede vivir en casa y autocuidarse con ayuda variable	70	Cuida de sí mismo pero es incapaz de llevar a cabo una actividad o trabajo normal
	60	Necesita ayuda ocasional de otros pero es capaz de cuidar de sí mismo para la mayor parte de sus necesidades
	50	Requiere ayuda considerable de otros y cuidados especiales frecuentes
Incapaz de autocuidarse. Requiere cuidados especiales, susceptible de hospitalización. Probable avance rápido de enfermedad	40	Incapacitado. Requiere cuidados especiales
	30	Severamente incapacitado. Indicación de hospitalización aunque no hay indicios de muerte inminente
	20	Gravemente enfermo. Necesita asistencia activa de soporte

	10	Moribundo
	0	Fallecido

En tu opinión, ¿cómo ha ido la consulta con el paciente?

Muy bien										Muy mal
100	90	80	70	60	50	40	30	20	10	0

7.3. Appendix C

Identificador:

Sexo:

- Hombre
 Mujer
 Otro

País de origen

Nivel de estudios:

- Primarios
 Secundarios/bachillerato
 Formación Profesional
 Universitarios

Primera consultata

Consulta de seguimiento

Edad: _____

Pareja:

- Sin pareja estable
 Pareja estable
 Casado/a
 Separado/a, Divorciado/a
 Viudo

Situación Laboral:

- Empleado por cuenta propia
 Empleado por cuenta ajena
 Pensionista
 Desempleado
 Otros _____

Razón de consulta:

Preguntas sobre salud

1. En general, diría que su salud es:

- Excelente Muy buena Buena Regular Mala

Las siguientes preguntas se refieren a actividades o cosas que usted podría hacer en un día normal. ¿Su salud actual le limita para hacer esas actividades o cosas? Si es así, ¿cuánto?

Actividades	Si, me limita mucho	Sí, me limita un poco	No me limita
2. Esfuerzos intensos (correr, levantar objetos pesados o participar en deportes agotadores)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Esfuerzos moderados (mover una mesa, pasar la aspiradora, jugar a los bolos o caminar más de 1 hora)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Coger o llevar la bolsa de la compra	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Subir varios pisos por la escalera	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. Subir un solo piso por la escalera	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Agacharse o arrodillarse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Caminar 1 km o más	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Caminar varias manzanas (varios centenares de metros)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Caminar una sola manzana (unos 100 metros)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Bañarse o vestirse por sí mismo	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Durante las 4 últimas semanas ¿ha tenido algunos de los siguientes problemas en su trabajo o en sus actividades cotidianas, a causa de su salud física?

	Si	No
12. ¿Hizo menos de lo que hubiera querido hacer?	<input type="checkbox"/>	<input type="checkbox"/>
13. ¿Tuvo que dejar de hacer tareas en su trabajo o en sus actividades cotidianas?	<input type="checkbox"/>	<input type="checkbox"/>

Durante las 4 últimas semanas ¿ha tenido alguno de los siguientes problemas en su trabajo o en sus actividades cotidianas, a causa de algún problema emocional (estar triste, deprimido o nervioso)?

	Si	No
14. ¿Hizo menos de lo que hubiera querido hacer, <i>por algún problema emocional?</i>	<input type="checkbox"/>	<input type="checkbox"/>
15. ¿No hizo su trabajo o sus actividades cotidianas tan cuidadosamente como de costumbre, <i>por algún problema emocional?</i>	<input type="checkbox"/>	<input type="checkbox"/>

16. Durante las 4 últimas semanas, ¿hasta qué punto su salud física o los problemas emocionales han dificultado sus actividades sociales habituales con la familia, los amigos, los vecinos u otras personas?

Nada Un poco Regular Bastante Mucho

17. Durante las 4 últimas semanas, ¿hasta qué punto *el dolor* le ha dificultado su trabajo habitual (incluido el estar fuera de casa y las tareas domésticas)?

Nada Un poco Regular Bastante Mucho

Las preguntas que siguen se refieren a cómo se ha sentido y cómo le han ido las cosas durante las últimas 4 semanas. En cada pregunta responda lo que más se parezca a cómo se ha sentido usted. Durante las últimas 4 semanas, ¿cuánto tiempo...

	Siempre	Casi Siempre	Muchas veces	Algunas veces	Sólo alguna vez	Nunca
18. ...se sintió calmado y tranquilo?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. ...tuvo mucha energía?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. ...se sintió desanimado y triste?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Por favor, señale de la lista de problemas que aparecen a continuación la alternativa que mejor describa en qué grado ha estado molesto/a o cuánto ha sufrido, **durante los últimos 7 días.**

Me he sentido molesto/a por:	Nada	Poco	Regular	Bastante	Mucho
1. Sensación de desmayo o mareos	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. No sentir interés por las cosas	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Nerviosismo o temblor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Dolores en el corazón o en el pecho	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Sentirse solo	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Sentirse tenso o alterado	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Nauseas o malestar en el estómago	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Sentimientos de tristeza	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Sustos repentinos y sin razón	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Falta de aire	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Sentir que usted no vale para nada	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Ataques de terror o pánico	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Adormecimiento u hormigueo en ciertas partes del cuerpo	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Sentirse sin esperanza en el futuro	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Sentirse tan inquieto que no puede permanecer sentado	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Sentirse débil en partes del cuerpo	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Pensamientos de poner fin a su vida	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

18. Sentirse con miedo	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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¡ATENCIÓN! ESTE CUESTIONARIO SOLO PUEDE ADMINISTRARSE DESPUÉS DE LA CONSULTA

Durante la consulta...

	Totalmente en desacuerdo	En desacuerdo	Parcialmente de acuerdo	De acuerdo	Totalmente de acuerdo
1. El médico me ha ayudado	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. El médico ha tenido suficiente tiempo para mi	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Creo en lo que me ha dicho el médico	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. El médico me ha entendido	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. El médico se ha dedicado a ayudarme	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. El médico y yo hemos estado de acuerdo sobre la naturaleza de mis síntomas	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. He podido hablar con el médico	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Me siento contento/a con el tratamiento del médico	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. He sentido al médico fácilmente accesible	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Teléfono y/o correo electrónico para participar en actividades de seguimiento (opcional)

7.4. Appendix D

Table D 1

Codes and Definitions for Patient Theme One: 'Illness, Emotional and Personal Problems'

Codes	Definition
Physical-emotional problems	Fragments of narratives that illustrate that a physical illness can cause emotional problems.
Acceptance of symptoms	Fragments that refer to the incorporation of symptoms into daily life or adapting living habits due to these symptoms.
Emotional consequences	Fragments of the narratives that highlight the consequences that the digestive disorder has on the mood of the person suffering from this disorder.
Relationship-consequences	Fragments of narratives that refer to the fact that the digestive disorder affects personal relationships, as well as to the way in which the person relates to others.
Consequences-daily life	Fragments of narratives that exemplify the consequences that a digestive disorder has on daily activities (i.e., on work, leisure and travel).
Stomach upset-stressful events	Narratives that refer to a suspected link between a stressful life event and stomach discomfort.

Emotional/personal problems	Fragments of narrative from patients that refer to the existence of emotional (e.g., anxiety, depression) or personal problems (e.g., unemployment, marital problems, bereavement, medication, alcohol and drug abuse).
Experience of the disease	Fragments of narrative that indicate that each person lives with their illness or symptoms depending on how they interpret them. Additionally, this refers to the extent to which it affects the patient or occupies a central place in their life.

Table D 2

Codes and Definitions for Patient Theme Two: 'Disease-Healthcare System Interaction'

Codes	Definition
Empathy towards professionals	Fragments of narratives in which patients express an understanding towards health professionals. This refers to the way in which personal problems or an excessive workload can affect the way in which physicians treat patients.
Uncertainty over waiting times	Parts of the narrative that refer to the fact that delays in medical test results or waiting periods until the next medical consultation causes uncertainty and concern for the patient.
Dissatisfaction with professionals	Fragments of narrative in which patients express dissatisfaction with the treatment or quality of care that they receive.
Dissatisfaction with treatment	Fragments of narratives in which patients express dissatisfaction with prescribed treatment.
Discomfort-absence of diagnosis	Fragments relating to the existence of stomach problems and discomfort without a cause after diagnostic tests have been carried out.
The need for patient strategies	Fragments in which patients express the need for tools and strategies in order to cope with the disease.

Satisfaction with professionals	Parts of the narrative that refer to the satisfaction with the treatment and quality of health care received.
Feelings of isolation/abandonment	Fragments that refer to the feeling of abandonment and lack of accompaniment by health professions and the health system in certain disease processes.
The feeling of being understood	Fragments that refer to the sensation that health professionals strive to understand the patient's discomfort and their situation.
Feeling misunderstood	Fragments that allude to the feeling that professionals do not understand the patient's situation or discomfort (i.e., they do not empathise with them or take them seriously).
Veracity of complaints	Parts of fragments that refer to the patient's belief that professionals think that they exaggerate their discomfort, or do not take their discomfort seriously.

Table D 3*Codes and Definitions for Patient Theme Three: 'Health System'*

Codes	Definition
Comprehensive care	Fragments that refer to the intervention as being of an integral nature such as seeing the person as a whole, taking into account psychological aspects, and the personal life of the patient.
Lack of clarity	Parts that refer to a lack of clarity in the explanations given by professionals regarding the disease and the steps that patients have to take in order to move closer to the healing process.
Consultation time	Fragments that refer to the healthcare professional taking the time that is deemed necessary, which is dependent on the patient's needs rather than what has been stipulated.
Generational change	This refers to the perception that new generations of professionals should work more closely with patients, use a more suitable communication style and greater clarity in their explanations.
Communication with professionals	This outlines the need for a suitable communication style with the healthcare professional as this facilitates understanding, the diagnostic process, the search for treatment, and provides peace of mind to the patient.

Coordination between services	This refers to collaboration and communication among health professionals regarding patients that they are both treating.
Difficulty accessing specialists	Fragments of narratives that make reference to the difficulties that patients face when requiring access to or when needing to be referred to specialists.
Not listened to enough	This refers to professionals not listening to patients and overlooking important information.
Lack of resources	The patient has given the impression that the public health system has worsened due to a lack of economic resources.
Inaccessibility of the professional	Refers to the belief that healthcare professionals feel that they are superior to patients.
Waiting lists	This refers to the time it takes to ask for a doctor's appointment until the time you have one which is considered as being too long.
Health insurance	This refers to the preference of being cared for by the Social Security system instead of using private health insurance in order to obtain the best quality of care. It also refers to the link between having health insurance and not having to wait to be seen.
Participation in studies	Parts of the narratives that allude to patient involvement in research studies.
Possible negligence	Fragments of text that refer to the existence of possible medical malpractice.

Table D 4*Codes and Definitions for Physician Theme One: 'Intervention'*

Codes	Definition
Openness with the patient	Fragments of text that refer to the importance of having a clear and honest communication style when discussing the patient's disease and symptoms.
Understanding	This relates to the fragments of text that exemplify the work the professional does to understand the patient and thus help the patient better understand their illness.
Differences in explanation	Fragments of narratives that expose the need of using different strategies to explain the diagnosis for patients with functional digestive disorders due to the difficulty of understanding this disorder.
Difficulty with the diagnosis	Parts of the narrative in which the difficulty that exists in making a diagnosis is based on the prevalence of the disease.
Difficulties with the doctor-patient relationship	Fragments that refer to the difficulty of establishing a good relationship with the patient.
Empower	Fragments of the narrative that refer to the work that healthcare professionals must do in order for the patient to take responsibility for what happens to them and must not have a passive role.

Lack of tools	Parts of the narrative referring to the lack of communication resources and tools for managing characteristics inherent to patients with functional digestive disorders.
Medical record	Fragments of the narrative that refer to the notes that professionals make in the medical records. This is in order to remind themselves of the patient's previous consultations or to make it easier for their colleagues.
Importance of the diagnosis	Fragments of the narrative that considers that a good explanation, understanding and internalisation of the diagnosis by the patient is key throughout the process.
The importance of a relationship	This refers to fragments of text outlining the importance of a good relationship between the physician and the patient. This needs to be based on trust, which is especially important in the intervention process for patients with functional digestive disorders.
Comprehensive intervention	Reflects the need and importance of treatment that integrates physical, psychological and personal aspects.
The need for more time with patients with FGIDs	Fragments of narratives in which professionals express that more time is needed when working with patients with functional digestive disorders as it is important to give them a good explanation of their pathology and create a good patient-physician bond.
Reassurance	The fragments of text that refer to the part of the intervention that involves reassuring patients by

	explaining to them that they will not suffer from a life-threatening illness.
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Table D 5*Codes and Definitions for Physician Theme Two: 'Patients'*

Codes	Definition
Adherence to treatment	Fragments of narrative which outline the importance for patients to follow guidelines and treatment prescribed by the physician. This also refers to the difficulties that physicians face in ensuring that patients keep to it.
Differentiating characteristics	These fragments exemplify the characteristics of digestive disorders, as well as patients who have digestive disorders. This leads to differences to other types of disorders when communicating and carrying out interventions with this subgroup of patients.
Disease awareness	Fragments of narrative highlighting the need to raise awareness of the presence of the disorder and the importance of following a treatment.
Mistrust	Parts of the narrative in which the mistrust that the patients have is felt by the physicians. This mistrust is either towards the physicians themselves, or towards the diagnosis or medication which is being given to them.
Gender difference	Fragments of text that refers to the differences observed by professionals when treating males and females in terms of adherence to treatment.

Brain-gut axis	Fragments of narratives that refer to the implications of the brain-gut axis on the intervention for patients with functional digestive disorders. As well as reference to the two different systems intervening.
Importance of psychological aspects	Parts of the narrative that refer to the influence of emotional discomfort (i.e., stress, anxiety, depression, personal situations) on digestive problems.
Importance of sociodemographic characteristics	Fragments of the narrative that refer to the importance of sociodemographic characteristics and the patient's background in explaining the disease, treatment, and to be able to intervene appropriately.
Non-acceptance of diagnosis	Fragments of the narrative exposing the difficulty with which patients find themselves accepting their FGID diagnosis due to its characteristics and chronicity.
Personality pattern	This refers to fragments of text that outline the existence of a specific personality pattern and a way of relating to the environment for patients with FGIDs.

Table D 6*Codes and Definitions for Physician Theme Three: 'Health system'*

Codes	Definition
Lack of mental health referral resources	Fragments of text that make reference to the difficulties that physicians face when referring patients with mental health problems to mental health services.
GP	Fragments of narrative reflecting the importance of the GP's support, as they know the patient and family better.
Biomedical models-chronic disease	Fragments of narratives exposing the need of changing the paradigm from a biomedical model to a biopsychosocial model as it is more suited to the needs of patients with chronic diseases.
The need of a psychologist	Fragments of narratives exposing the need for a primary care psychologist due to the prevalence of emotional problems that have been observed in patients.
Overload-consequences	Fragments of text that refer to the consequences of having an excess of patients and the effect that this has on the quality of care.